



**Policy, Politics and Patients:  
Public Policy and Radiation Therapy Services in North  
West Tasmania**

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Submitted in fulfilment of the requirements for the degree of  
Doctor of Philosophy

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### ***Journal Articles***

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### ***Selected refereed conference papers***

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## Dedication

To Caroline – your journey was the inspiration for this research. As I continue along down this shared path we will forever have I only hope to do you justice.



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# Glossary of Terms

ACF	Advocacy Coalition Framework
AMA	Australian Medical Association
ANMF	Australian Nursing and Midwifery Federation
CCA	Community and Community Advocates
DC	Deep Core Belief
DHHS	Department of Health and Human Services (Tasmania)
FHPA	Federal Health Policy Actor
FTE	Full time equivalent
HHF	Health and Hospitals Fund
HREC	Human Research Ethics Committee
HP	Health Professional
LGH	Launceston General Hospital
LINAC	Linear Accelerator
MCH	Mersey Community Hospital
NHMRC	National Health and Medical Research Council
NPF	Narrative Policy Framework
NW	North West
NWRCC	North West Regional Cancer Centre
NWRH	North West Regional Hospital
PC	Policy Core Belief
RHH	Royal Hobart Hospital
SA	Secondary Aspects
SHPA	State Health Policy Actor

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# Abstract

In 2010 the Federal Government made a major funding commitment that enabled a local radiation therapy service to be built in North West Tasmania. This changed the geographic accessibility of radiation therapy services for the region's residents as well as the overall design of cancer services for North West Tasmania. The establishment of this service came about despite the North West's small population, proximity to existing radiation therapy services in the North, long-standing issues with recruitment and retention of specialist health staff, and strong opposition from health professional groups. The aim of this research was therefore to examine how and why public policy responded to the issue of geographic accessibility of radiation therapy services in regional North West Tasmania, with particular regard to the establishment of the North West Regional Cancer Centre.

To understand this policy change, a policy analysis framework – the Advocacy Coalition Framework, developed by Paul Sabatier – was utilised and its hypotheses tested against the case study of radiation therapy services in North West Tasmania. The Advocacy Coalition Framework is premised on actors forming coalitions with others based on shared policy beliefs, and it is these coalitions that engage in non-trivial action to influence policy outcomes.

The research was based on a descriptive case study using document analysis and semi-structured interviews with key stakeholders and patients and their family. This yielded 137 relevant documents for analysis and interviews with 38 participants. An analysis of documents and interview transcripts was done using the Advocacy Coalition Framework to ascribe beliefs and thereby determine the coalitions involved in the debate over radiation therapy services in North West Tasmania.

The findings indicated the clear presence of one coalition, comprising of state health policy actors and health professionals. This coalition shared a core belief of advocating for safety and sustainability of radiation therapy services, with a North West service considered largely unfeasible prior to the 2010 funding commitment. There was no evidence to indicate a second coalition comprising of identifiable actors engaged together in non-trivial action to

advocate for a North West service. The findings did indicate a strong role for the media as well as intervention by the Federal Government in an area of State responsibility.

The results suggest that political strategy, brought about by internal and external subsystem events, was the impetus for policy change in regard to radiation therapy services in North West Tasmania. It also found that local sentiments and a boundedly rational decision-making process added to this outcome by giving weight to the desire for a local radiation therapy service in policy decision-making rather than alternative means to deliver such a service to the patients in that region.

This research was limited by geographical region, looking solely at patients who reside or resided or resided in North West Tasmania at the time of diagnosis. The research also focused on only one diagnosis type – cancer, in its multiple forms – and only on treatment, not prevention, screening or education. The research also related to public policies, without consideration of private and organisational policies that may impact on service delivery or design. The sample for interviews was limited by the opt-in nature of the patient and family recruitment strategy, meaning only those who became aware of the research and wished to participate were able to be recruited.

This research applies then critically reviews the Advocacy Coalition Framework. In particular, the Framework considers the policy subsystem to comprise of two or more formal coalitions that vie for policy influence by utilising opportunities and resources. This case study identified only one coalition, and the implementation of a policy change was contrary to the objectives of that single coalition. This challenges the notion that two or more formal coalitions are required to achieve policy change and supports the hypothesis that policy remains unchanged whilst the jurisdiction that instigated it remains, unless change is imposed by a hierarchically superior jurisdiction. This thesis extends our understanding of localism and the influence of policy entrepreneurs in effecting policy outcomes, in this case, the introduction of a local radiation therapy service to North West Tasmania.

# Chapter 1: Introduction

This research examines why a policy change, the establishment of the North West Regional Cancer Centre, was made that affected radiation therapy services in regional North West Tasmania, Australia, and in particular the geographic accessibility of these services. In 2010 the federal government's major funding commitment for a local radiation therapy service to be built in North West Tasmania changed the accessibility of radiation therapy services for the region's residents as well as the overall design of cancer services for the area.

Understanding the reasoning and motivation behind this funding commitment is integral to understanding why public policy responded to the issue in the way it did: was a local service a necessary public policy response to the problems encountered by this group of Australians, or were there other underlying motivations?

Using Sabatier's Advocacy Coalition Framework (ACF), this thesis will examine why various policy decisions were made and implemented, and under what influences, to create the system of cancer services available in Tasmania today. From this understanding of decision-making platforms will come a demonstration of motivations and thereby a deeper understanding of the process of policy change, in this case as it applies to cancer services in North West Tasmania. The ACF was selected as the most appropriate theory for analysis for the following reasons: the capacity to define the policy subsystem by policy area, geographic area and active policy actors; clear definition of what constitutes a coalition; clear definition of what constitutes the beliefs of coalitions; capacity to categorise and prioritise beliefs; and scope to consider impacts from within and beyond the subsystem to determine policy changes.

Three key concepts will inform the research question:

*Public Policy* is considered as formal policies, policy commitments and policy debate relating to the development of a local radiation therapy service in North West Tasmania.

*Accessibility* refers to geographic accessibility, or the proximity of patients and services.

*Radiation Therapy Services* refers to the debate over whether to establish a local service in the North West region to provide local treatment to cancer patients there, rather than requiring them to access the service in another region.

## Research Question

Why was the policy decision made to establish radiation therapy services in North West Tasmania in 2016?

## Statement of the Problem

In 2014 cancer accounted for approximately three in ten deaths in Australia and contributed to 19% of Australia's total disease burden (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries 2017). In its simplest form, cancer is a disease of the body's cells—and is a term that covers approximately 100 different diseases in which abnormal cells develop, reproduce and spread (Australian Bureau of Statistics 2006). In a social context, the word 'cancer' evokes indiscriminate victim selection, prolonged suffering, familial heartbreak, and an often-unknown prognosis. The word carries a strong psychological response and stigma (Radiation Oncology Inquiry 2002).

Treatment of cancer can include any combination of medication, surgical intervention, chemotherapy, radiation therapy or palliation. Chemotherapy is the administration of drugs (known as cytotoxic drugs) designed to kill cancer cells (Cancer Council Australia 2016). The drugs can be administered orally, intravenously, by direct application to tissue, or topically. Radiation therapy involves radiation targeted at specific sites in the body, to kill or damage cancer cells (Australian Institute of Health and Welfare 2016). It is delivered by radiation therapists under the supervision of a radiation oncologist and is usually provided as an outpatient service over a specified period of time. Both chemotherapy and radiation therapy are common treatments for cancer and can be prescribed individually, together, or in conjunction with surgery.

While particular age groups and genders carry specific levels of risk for certain cancers, old age is the largest risk of all. In 2011, 54% of all cancer patients diagnosed were over the age

of 65 (Stavrou et al. 2012). In 2013, Australians over 85 had a one in two chance of being diagnosed with cancer (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries 2017). Two thirds of all new cancer cases in 2017 were estimated to be in those aged 60 or over (Australian Institute of Health and Welfare 2017), and two thirds of them were likely to have a comorbidity (Stavrou et al. 2012).

This has strong implications for rises in incidence and prevalence as the population ages, as well as for cancer service design and delivery as community expectations respond to this prevalence and shape demand for services. It also has implications for health policy and resource allocation. An aging demographic means an ever-larger cohort of the most cancer-prone section of the population. Higher levels of public awareness about the dangers of cancer increase the demand for screening and, subsequently, treatment. Lifestyle factors increase the risk of cancer (Cancer Australia 2013), and aging is often positively correlated with comorbidities that may limit treatment and shorten survival (Stavrou et al. 2012).

Australians are likely to reach the age where cancer is a possible diagnosis, and to expect a full range of treatment options if it is indeed diagnosed. This expectation will strain service design and resource distribution.

This strain is already evident in health funding. Health spending grew 1.7 times higher in real terms in 2001–02 and 2011–12, at an average rate of 5.4% per annum compared with only a 3.1% growth in GDP (Australian Institute of Health and Welfare 2014a). Cancer was the sixth highest disease group by expenditure between 2008 and 2009, costing approximately \$4.5 billion, or 7% of the total health expenditure (Australian Institute of Health and Welfare 2013b). In that same financial year, expenditure on those aged over 85 was 20 times higher per person than on children aged 5–14 (Australian Institute of Health and Welfare 2014a), indicating the cost burden of an aging population with increased incidences of cancer.

Cancer services are, to some extent, stuck between the logic of what should be and the reality of what is. While it could be argued that finite resources should be aimed at treating the most treatable, or those with the ‘most to lose’, such as children or young adults, in reality health expenditure on cancer services is largely consumed by older age groups. In 2008–09 (the most recent data available in 2017) only 2.7% of total health expenditure on cancer was incurred by the 0–14 age group, 1.8% by the 15–24 group, 41.4% by the 25–64

group, and 54.1% by the 65 and over group (Australian Institute of Health and Welfare 2013b); and of this 54.1%, 75.6% was expended on in-hospital treatment (Australian Institute of Health and Welfare 2013b). Over half the total financial, physical and human resources were expended on the older population.

## Incidence and Prevalence

Seeking to understand the prevalence and incidence of different cancers is an important step in health care planning and service delivery. The National Cancer Institute (n.d.) defines prevalence as ‘the number or percent of people alive on a certain date in a population who previously had a diagnosis of the disease’, and incidence as ‘the number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 population at risk’. Prevalence naturally dictates demand for services, while incidence can indicate likely changes in prevalence and future demand (Australian Institute of Health and Welfare 2012c). Statistical information on incidence of cancer is more readily available and comparable than data on prevalence.

## National Context

Australia ranked third among age-standardised rates of cancer worldwide in 2012, just behind Denmark and France (323 per 100,000 people) (World Cancer Research Fund International n.d.). The Australian figure was 400 per 100,000 females and nearly 600 for males, when non-melanoma skin cancer was included (a cancer type that is excluded from the GLOBOCAN global data of 2008) (Australian Institute of Health and Welfare 2012b). This rate was predicted to drop to 470 for both genders combined in 2017 (Australian Institute of Health and Welfare 2017). When grouped regionally, Australia ranked first in 2008, ahead of New Zealand, Northern America and Western Europe (Australian Institute of Health and Welfare 2012b). Some commentators put this down to Australia’s legislative requirements regarding cancer as a notifiable disease, well promoted screening programs, and the relative strength of Australia’s cancer data (Australian Institute of Health and Welfare 2012b; OECD 2011); such national variations can create methodological challenges when trying compare surveillance, screening and reporting of cancer rates between countries.

While Australia was above the global average for rates of incidence (approximately 310 per 100,000, compared to less than 200 per 100,000), it fell below the global average in cancer-related mortality (110 globally versus just over 100 per 100,000 in Australia) (Australian Institute of Health and Welfare 2012b). Nevertheless, cancer continues to feature heavily in Australian mortality statistics: it was the second most common cause of death in 2014, (29% of all deaths) (Australian Institute of Health and Welfare 2017). It is estimated that cancer will take the lives of 47,753 Australians in 2017. Males still represent more than half of cancer-related mortalities at 57%. Lung, colorectal, pancreatic, prostate and breast cancer are the most common cancer-related causes of death, and are estimated to make up 47% of all cancer mortality in 2017.

### Tasmanian Context

Tasmania experiences the same prevalence of certain cancers as the rest of the nation, but fares poorly in terms of incidence. Tasmania had the second highest incidence of combined cancers between 2008–12, at 517 per 100,000 persons, once size and age structure were taken into account; and the highest rate for colorectal, kidney and bladder cancers (Australian Institute of Health and Welfare 2017). It also had the second highest incidence of cancer-related mortality, behind Northern Territory, with 189 deaths per 100,000 people between 2010 and 2014. It was the most common cause of death in Tasmania in 2015, accounting for 30.2% of all deaths (Australian Bureau of Statistics 2016).

With distance from Hobart, socio-economic determinants of poorer health outcomes (smoking, diet, education, teen pregnancy) increase. Health outcomes tend to be poorer in people living in remote areas compared to those in metropolitan areas. Factors that may explain this difference include geographic isolation, quality of transport networks, and lack of access to health professionals and health services. Typically, the most health-disadvantaged people have the least ready access to health services (North West Radiotherapy Clinical Expert Panel 2011, 14).

Tasmania equals South Australia in having the oldest population in Australia, and the older age groups are expected to be responsible for most of the minimal overall population growth (Australian Bureau of Statistics 2011). Given the established association between age

and cancer incidence, this will create a higher demand for cancer treatment services in Tasmania. Tasmanian cancer patients' travel to infusion services (chemotherapy) was mapped in 2011, with the North West electorate of Braddon sitting third of the five Tasmanian electorates. However, Braddon fared worst in travel to radiotherapy services, at 129.5km on average compared to the state average of 52.9km (Deloitte Access Economics 2011). However, distances travelled to access radiation therapy or chemotherapy in Tasmania remained below the national average, even for those in the North West (Deloitte Access Economics 2011), indicating that travel to treatment was not as significant as it perhaps was in other states.

### North West Tasmanian Context

North West Tasmania is classified as RA3 *Outer Regional* along most of the coastline, RA4 *Remote* along the West Coast, and RA5 *Very Remote* on King Island (DoctorConnect n.d.), making it the most rural of the three regions in Tasmania. Residents of North West Tasmania are therefore considered rural and regional patients, and living in a rural or regional area creates issues for accessibility of health services. The regional dilemma for patients is evident in their diagnosis and mortality rates. In 2010–14, those living in very remote areas had a higher age-standardised mortality rate for many cancer types than those living in major cities (Australian Institute of Health and Welfare 2017). This was compounded by the link between remoteness and lower socioeconomic status, as well as by risky health behaviours in regional and remote areas such as smoking, alcohol use and poor nutrition. North West Tasmania has two of the most socioeconomically disadvantaged regional centres in Australia, Burnie and Devonport (Brindley & Turner 2015), and this disadvantage is intrinsically related to poor lifestyle risk factors that impact on cancer incidence.

While incidence and mortality for cancer in the North West (23% of the state-wide population) compares equally with the remainder of the state, there are significant lifestyle-related risk factors that are cause for concern (Tasmanian Health Organisation - North West 2013). For example, in 2009 the Tasmanian rates of daily smoking, excessive alcohol consumption, insufficient physical activity and inadequate vegetable consumption were all higher in the North West than in the rest of the state (Tasmanian Health Organisation -



North West 2013). This was particularly notable for smoking, with 17.4% of the North West population identified as daily smokers, compared to 16.2% Tasmania-wide.

The combination of remoteness, socioeconomic status and risky health behaviours creates a need for fair access to cancer treatment service for residents of North West Tasmania, including radiation therapy services. The question is how and why public policy responded to this need by establishing a local radiation therapy service. Was a local service a necessary public policy response when the distances travelled were lower than the national norm, or were there other motivations behind it?

## Overview of Research Methodology

### Research Design

The research is based on a descriptive case study that used both document analysis and semi-structured interviews with key stakeholders and patients and their families. Stakeholders were interviewed due to their high degree of involvement in the design, delivery or advocacy of cancer services in Tasmania. Patients and family were included in this method of data collection to determine if there was evidence of community-level involvement in advocating for changes to cancer service delivery. An analysis of policy documents, government reports and other grey literature was done using the Advocacy Coalition Framework (ACF), developed by Paul Sabatier, as the analytical framework (Sabatier 1986). Under the ACF, policy change takes place amidst policy sub-systems bound by relatively stable parameters which still may be affected by major external events (Buse, Mays & Walt 2012). The ACF centres policy debate on conflict between advocacy coalitions which can include a broad range of actors, from politicians and bureaucrats to community groups, researchers and professional bodies, and are bound by a common set of beliefs and values. These common beliefs and perceptual filters can alter the way in which the same information may be processed and set views reinforced, such as the right to universal health care or the need to keep major services centralised (Sabatier & Weible 2007). Such entrenched perceptions help explain why there is always ongoing policy conflict.

Interviews using open-ended questions and additional prompts were used when talking to patients/family and stakeholders of cancer services in Tasmania. Basic demographic information, such as gender, work status, and mobility status, was gained through observation or prompts when answering questions. The interview transcripts were also analysed using the ACF.

## Setting

North West Tasmania is the setting for this research. Stakeholders—those involved in the design, delivery or advocacy of cancer services in North West Tasmania—were interviewed in their workplaces (unless they requested otherwise) to highlight the connection between their work and their involvement in the establishment of a radiation therapy service.

Stakeholders were selected with reference to their work in or around cancer services, so the workplace seemed the most appropriate venue. Patients/family/carers were interviewed at home to encourage a sense of security and familiarity in the interviewee, as well as a degree of privacy when discussing personal issues relating to their experiences. Only the interviewee and the interviewer (the doctoral candidate) were present, unless otherwise requested.

## Sample and Recruitment

Stakeholders—those involved in the design or delivery of the service—were recruited using purposive snowball sampling and a direct letter of invitation to participate in an interview. The selection of stakeholders was, in part, theoretically derived, based on the ACF; and the participants represented key figures in the main coalitions or advocacy groups involved in the debate.

Patients/family were recruited via an opt-in system with an advertisement placed in local newspapers and fliers placed in the North West Regional Cancer Centre and in regional community health centres and support services, such as Cancer Council Tasmania. There was no direct approach to patients/family, in accordance with the ethical standards established by the Human Research Ethics Committee, to avoid the possibility that people might feel pressured to participate.

## Data Collection and Analysis

To determine interplay between community expectations, accessibility issues and government policy agendas, the doctoral candidate applied the ACF to the analysis of the issue and its actors. Coalitions were identified through document analysis and interviews, belief systems attributed to each, and a history of action by each coalition built to determine policy-oriented learning, core and secondary beliefs, strategies for promoting policies, and the resources held by each that could influence the policy debate. Language and narratives were examined to determine how they had been used to sway opinion or gather support for policy proposals.

Documents were collected using relevant databases, key words, booleans and limiters. Manual searches were also conducted as further documents were identified and retrieved. These documents focused on the delivery of cancer services and, more specifically, of radiation therapy, in Tasmania; the history of health care reform in Tasmania; rural health disparities; the unique political context in Tasmania that promoted local issues; and the application of the ACF to health policy.

Interviews were done face-to-face and were audio recorded with participants' consent. They were conducted at the patient/family member's home or stakeholder's workplace unless an alternative venue was requested. An information sheet was provided and a consent form was signed by both the participant and the interviewer at the start of the interview.

Interviews with stakeholders and patients/family focused on the stakeholders' and patients'/families' experiences with radiation therapy services and any impediments to access. These subjective experiences were grouped according to patterns identified across the interviews, to create categories or common themes. These themes were compared with the actions and beliefs of key coalitions in the debate over radiation therapy services to determine how accessible the system is, and is perceived to be.

## Structure of the Thesis

The structure of this research was as follows:

Chapter 1 – Introduction: a succinct discussion of the research problem highlights the need for appropriate and accessible radiation therapy services, but also of debate about the best distribution of resources to achieve accessibility. The research aims and question are introduced and the context of the research problem is provided to the reader.

Chapter 2 – Literature Review: a comprehensive literature review looks at relevant literature from a variety of sources to provide an understanding of rural and regional health disparities, Tasmania's unique political system, and the current state of Tasmania's cancer services. This chapter also provides a summary of key policy-making theories relevant to this case study, including the ACF that is used to evaluate the research question. The theories discussed are:

- ACF
- pluralism
- elitism
- punctuated equilibrium theory
- coalition structuring
- policy narratives framework
- bounded rationality
- localism.

Chapter 3 – Methodology: a comprehensive discussion of the processes and procedures employed to locate data and achieve rigour and quality is achieved in this chapter. The link between the data to be collected and the research aims is addressed.

Chapter 4 – Results I: documents from 2000 on, relating to the design and delivery of radiation therapy services in North West Tasmania, provide an initial source of data against which to test the research question.

Chapter 5 – Results II: stakeholder interviews offer insight into the values and beliefs of those actors most closely engaged in the provision and design of radiation therapy services in the North West, and into how these beliefs have or have not shaped this policy area. Patient and family interviews provide user feedback and perspective on the experience of

accessing these services in North West Tasmania and provide further insight into the possible effect of these perspectives on policy change.

Chapter 6 – Discussion: the key findings are discussed to explore their importance and relevance to the research question. Elements of the ACF are tested and suggestions are given on areas for future focus and development. These key findings question whether there was formal community involvement in the debate over whether to have a local radiation therapy service in North West Tasmania, and challenges the premise of the ACF that a policy subsystem consists of two or more formal coalitions vying for influence over the decision-making process. The discussion also summarises the key limitations of the research, including the scope of the research, the interpretation of findings, contradictions and conflicts, data collection, sample size and interviewer bias.

Chapter 7 – Conclusion: this chapter summarises the contribution of each chapter to the development of the research question and understanding of the answer. The key findings, strengths and limitations are re-examined to provide a holistic answer to the research aims.

## Chapter 2: Literature Review and Context

The purpose of the literature review is to ‘set the broad context of the study, clearly demarcate what is and what is not within the scope of the investigation, and justify those decisions’ (Boote & Beile 2005, 4). Wakefield (2014) describes the literature review as an opportunity to relate research to a larger body of knowledge, ‘filling in gaps’ and establishing the importance of the research question. The same literature also provides a context for the study and informs the reader of the people, place and history relevant to the research question.

This literature review endeavours to use key terms, a systematic search of the literature, and use of inclusion and exclusion criteria to create a substantive and relevant body of literature, including seminal works, which will form the foundation for this study. Analysis rests on the following topics: the history of cancer services in Tasmania; health discrepancies for rural and regional areas; health as policy; the history of planned health changes in Tasmania; and the policy cycle, theoretical frameworks and their application to health policy. The ACF is examined in greater detail as its application in the field of health policy is examined and confirmed, and ultimately selected as the primary analytical framework for radiation therapy services in North West Tasmania.

This review provides context on what radiation therapy and other cancer services have existed in Tasmania and how they developed over time, what changes have been attempted or implemented, and the impetus for these changes. It also examines how similar research has been conducted using the ACF, and identifies the questions or points this research raises for analysis of interaction with the North West Tasmania cancer policy subsystem.

The review follows a simple process of identifying those terms typically used in the literature; locating the literature; reading the literature and checking it for relevance; organising what is read into appropriate themes and subthemes; and writing the review (Creswell 2002). The search strategy below outlines the steps taken to gather literature in keeping with this process. Along with analysis of individual articles, the content needs to be discussed in context with what has been said collectively about the research question, so the

review does not limit itself to being a series of individual critiques with no broader, overarching analysis (Wakefield 2014).

## Search Strategy

The research aims outlined in Chapter 1 were used as the basis for designing keywords to be used in the initial data search. The search began with a discussion with a research librarian at the University of Tasmania who advised which were the best databases to use when looking at health and policy. An initial search of these databases using the search terms yielded results in excess of 2000 in some instances, too many results to study effectively. The search terms were then grouped into two sets: one to find literature relating to cancer services in Tasmania, and one to find literature relating to the application of the ACF to health policy issues. Scopus, EBSCO, PubMed, ProQuest, and APA were chosen to access relevant literature from peer-reviewed sources.

An additional measure was an experiment using a two-year time restriction to determine the database(s) most likely to yield the most results based on the keywords, before conducting a full literature search. The results are outlined in Tables 1 and 2:

**Table 1 Search results of pilot**

Search term: cancer + Tasmania + regional + policy, year 2005–07, English

	Scopus	EBSCO (inc CINAHL)	PubMed	ProQuest	APA
Title, abstract & keywords	0	0	0	0	0
All fields	9	103	0	201	0

**Table 2 Search results of pilot**

Search term: 'Advocacy Coalition' + 'cancer', year 2005–07, English

	Scopus	EBSCO (inc CINAHL)	PubMed	ProQuest	APA
Title, abstract & keywords	2	4	1	0	0
All fields	22	81	7	400	0
With change: Advocacy Coalition Framework	7	7	0	39	0

Of the databases, EBSCO (103 and 81 results) and ProQuest (81 and 400 results) were considered to be the two most likely to yield sufficient literature, and a full search was then done using them only, but with the literature extended to 1986–present for items using the search term 'Advocacy Coalition Framework', as this was the first year in which Sabatier wrote about the ACF (Sabatier 1986). The year 2000 was used as the time restriction for the search term 'cancer + Tasmania + regional + policy', as the ACF is premised on the study of policy issues over at least a decade (Jenkins-Smith & Sabatier 1994): timespans of less than a decade undermine proper evaluation, as a full policy cycle normally takes this long. Often what is early perceived as a failure of policy can be more favourably re-evaluated over a longer timeframe. Additionally, coalitions are better able to be identified and analysed after longer timespans which give actors time to settle into stable coalitions premised on shared beliefs and policy objectives. In 2010 a major funding decision impacting on the delivery of radiation therapy services in North West Tasmania had been announced, a commitment to build a Centre in Burnie; and the starting point of 2000 gives a full decade to consider the influences and impacts leading to this decision, as well as seven years after the funding commitment to view its implementation. The only exception to the year 2000 restriction was information specifically sought to create a historical picture of the development of cancer services within Tasmania. This information came from annual reports and related reports of the Department of Health and Human Services, examined at the Dr Richard Buttfield library in Burnie, Tasmania ( $n=11$  documents).

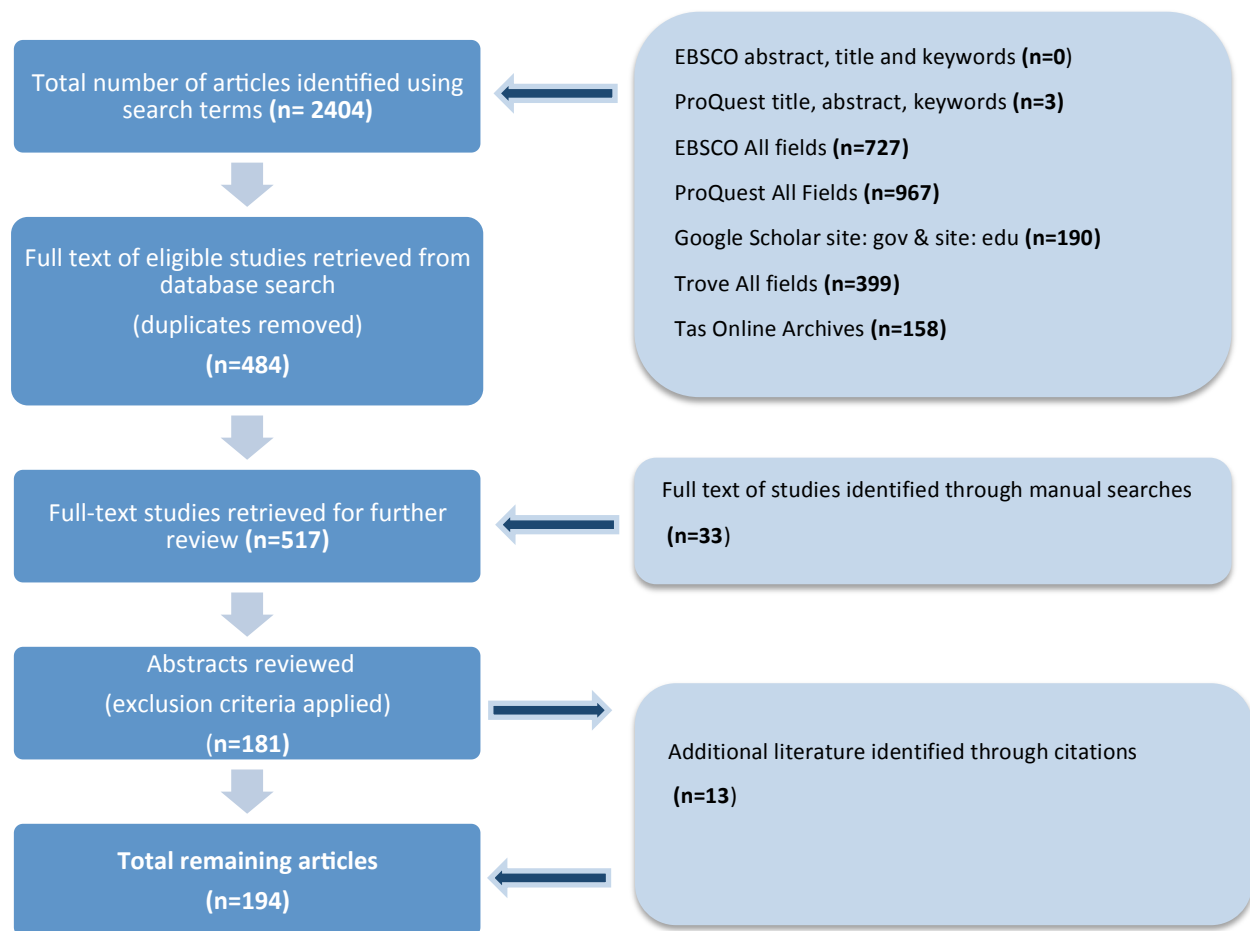


Google Scholar, the Tasmanian Online Archives and Trove (the database of the National Library of Australia) were added to the search sites, with filters for sites relating to government, organisational and educational literature, to capture relevant grey literature not accessible through traditional academic databases. For Google Scholar, the initial result was  $n=13,500$  results and the search terms were altered to change 'cancer' to 'cancer services', reducing the total to  $n=190$ . The full process of retrieving, reading and refining the results for the two searches is outlined in Table 3, and the results drawn from each stage of the process is outlined in Figures 1 and 2.

Grey literature was included as it is now heavily used and valued in policy work, and forms a key part of the evidence base (Lawrence et al. 2014). A survey of policy information users found that over 80% regularly used grey literature in their work (Lawrence et al. 2014), making it an integral part of any review dealing with policy analysis. Grey literature is defined as

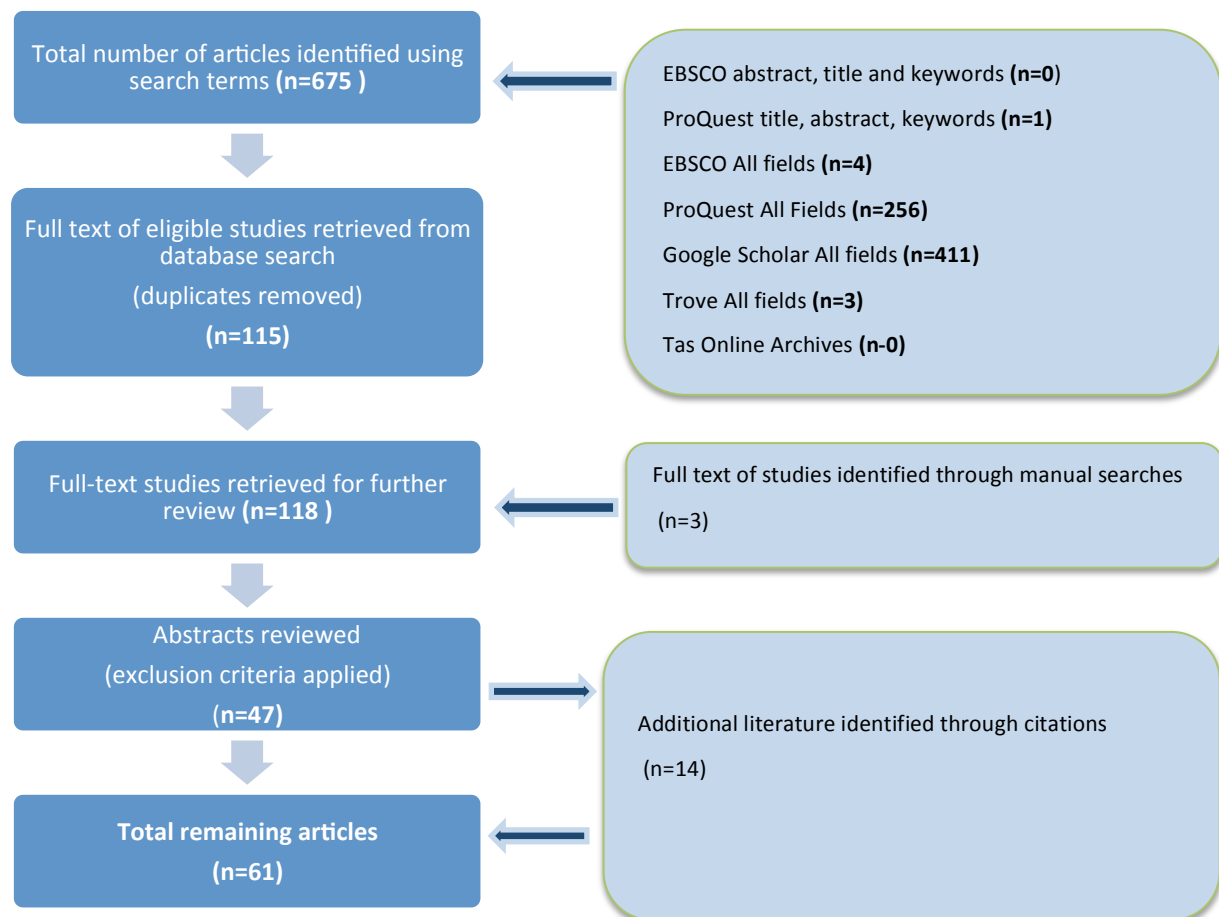
that which is produced at all levels by government, academia, business and industry, both in print and electronic formats, but which is not controlled by commercial publishing interests, and where publishing is not the primary business activity of the organisation. (Pindlowa & Cisek 1999)

Grey literature includes policy documents, government reports, theses, conference papers, data sets and corporate research. It is highly valued as a source of evidence in policy and health research as it is often the only source of current data that can be used by practitioners in program development; and it is published more quickly than formally published literature (Wallis 2004). It also covers issue areas not covered elsewhere in traditional published literature and is often free and readily accessible by users (Lawrence et al. 2014).



**Figure 1 Results of database search**

Search terms: cancer + Tasmania + policy + regional, English only, 2000–present



**Figure 2 Results of database search**

Search terms: 'Advocacy Coalition Framework' + cancer, English only, 1986–present

**Table 3 Literature search process**

Process	Detail
Sampling Strategy	Selective: Sample databases from nursing and public policy; manual searches; Google; Google Scholar; Trove; Tasmanian Online Archives
Type of Study	All qualitative and quantitative research as well as systematic reviews; all grey literature (reports, conference papers, theses, media articles, briefing papers, discussion papers, guides, data sets, working papers, policies, procedures)
Approaches	Key word searches; citation searches; manual searches of government and organisational websites
Range of years	2000–present 1986–present
Language	English only
Inclusion and Exclusion Criteria (See Appendix 1 for full list)	1986 onwards (ACF documents) 2000 onwards (cancer services documents) English only Full text, published documents Exclude non-melanoma skin cancers Treatment only, excluding prevention and education Exclude alternative therapies Tasmanian services only
Terms used	cancer + Tasmania + policy + regional Advocacy Coalition Framework + cancer
Electronic sources	EBSCO; ProQuest; Google; Google Scholar; Trove; Tasmanian Online Archives

(format sourced from Moran et al. 2014)

These tables provide a summary of the approach used to retrieve information to inform the literature review and provide context for the research question. This allows transparency and replication.

From this the literature can be grouped into the following topics for discussion:

- regional discrepancies in cancer services and outcomes, with North West Tasmania being a regional area
- a snapshot of cancer services in Tasmania, to understand what existed prior to the North West Regional Cancer Centre's opening as well as what exists presently
- the nature of health as a policy subset
- health reforms in Tasmania since 2000 and how these have shaped and been shaped by the political environment in Tasmania
- a chronology of events leading to the opening of the North West Regional Cancer Centre
- the unique aspects of Tasmania's political system that have had an impact on health reform and radiation therapy services
- the theoretical models and frameworks that are most applicable to the study of health policy.

## Cancer Services

### Regional Discrepancies In Cancer Services and Outcomes

Debate over the accessibility of oncology services in North West Tasmania is an extension of the overall debate on the health discrepancies between those living in metropolitan areas and those in regional and remote areas. The Australian Standard Geographical Classification–Remoteness Areas (ASGC–RA) system classifies areas as major cities, inner regional, outer regional, remote or very remote, based on the physical road distance to the nearest service centre (Council of Australian Governments Reform Council 2012). Tasmania has no major cities, and the North West is categorised as outer regional and remote.

It is estimated that 30% of people with cancer live outside major population centres; this puts them at a disadvantage in terms of survival (Rural Doctors Association of Australia 2005). Although the age-standardised incidence rate for all cancers is lowest in very remote areas (398 per 100,000), mortality rates are highest in remote and very remote areas (192 per 100,000) (Australian Institute of Health and Welfare 2014b). While good progress has

been made in decreasing overall cancer deaths in Australia, this has not equated to progress in reducing disadvantage in remote and regional areas (Coory, Ho & Jordan 2013), with patients from regional and remote areas 35% to 300% more likely to die within five years of diagnosis than their metropolitan counterparts, based on cancer type (Rural Doctors Association of Australia 2005).

Discrepancies in cancer outcomes for people in regional and remote areas do not relate solely to mortality. Patients from such areas are

- more likely to defer access to a GP for diagnosis, and are therefore diagnosed at a more advanced stage (Council of Australian Governments Reform Council 2013)
- less likely to have breast-conserving surgery in the case of breast cancers (Senate Community Affairs References Committee 2005)
- less likely to have any surgical interventions, and less likely to access radiotherapy treatment or be followed up by their treating specialist (Heathcote & Armstrong 2007)
- required to travel further and more frequently for treatment services
- more likely to experience delays in treatment; more likely to have poor continuity of care and poorer access to diagnostics
- less likely to complete a prescribed course of treatment (DLA Phillips Fox 2010)

To illustrate these discrepancies, one study of rectal cancer in New South Wales showed that of 60 patients from remote to very remotes areas referred for radiotherapy, 0% (zero) were actually treated (Heathcote & Armstrong 2007).

There are myriad identified reasons that can or do contribute to discrepancies in outcomes for regional and remote cancer patients. People from these areas are

- more likely to engage in modifiable risk factors such as poor diet, lack of exercise and smoking, which heighten the risk of developing cancer
- less likely to have access to public health education programs designed to mitigate such risks
- more likely to visit a GP who has limited knowledge of appropriate referral pathways (Senate Community Affairs References Committee 2005)

- more likely to be serviced by a GP with poor patient-to-doctor ratios, which can compromise screening opportunities (Rural Doctors Association of Australia 2005)
- isolated by geography and transport
- disadvantaged by a shortage of appropriate healthcare professionals
- less able to access the full array of screening and diagnostic services
- more likely to access a GP who is unable to recognise preliminary symptoms of cancer
- less able to access specialised treatments in their local areas and, where such services exist, they are less likely to be staffed by appropriate levels of specialised oncology staff (Deloitte Access Economics 2011)
- more likely to be Indigenous or from a lower socio-economic background, both of which are positively correlated with cancer incidence (Coory, Ho & Jordan 2013)
- more likely to decline treatment altogether (Hall et al. 2005)

A significant issue for people from regional and remote areas, and the issue that has particularly spearheaded calls for radiotherapy services to be delivered in North West Tasmania, is the burden of travel by patients to treatment. Treatment for cancer can be a time-consuming exercise, often requiring the patient to attend five days a week for up to eight weeks at a time (DLA Phillips Fox 2010). Numerous studies have linked travel with negative physical, psychological and financial outcomes for patients (Deloitte Access Economics 2011; Hall et al. 2005; Hegney et al. 2005; Payne, Jarrett & Jeffs 2000; Senate Community Affairs References Committee 2005). For those who are able to relocate to major centres to receive treatment, there is the issue of separation from family and social support networks during this time as well as the financial burden of relocation (Deloitte Access Economics 2011). A study of patients in Queensland in 2001 found that patients specifically pointed to the burden of travel, difficulties associated with living somewhere that is not their own home, the feeling of being a burden on others and the lack of closeness to family and friends (Hegney et al. 2005).

For those unable or unwilling to relocate, there are equal physical, emotional and financial burdens caused by travel. Patients pointed to travelling discomfort caused by burns and blisters from radiotherapy, fatigue, the inability to sit for prolonged periods after lower body

treatment. A study of breast cancer patients in rural South Australia found that 89% believed they had inadequate social and practical support, 61% did not receive any financial support for travel or accommodation, and 19% of those who did claim financial support had difficulties accessing it (Payne, Jarrett & Jeffs 2000). A similar study in Western Australia also highlighted that lack of information on the availability of financial support for travel was a common concern for patients (Hall et al. 2005).

For Tasmanian cancer patients, travel to infusion services (chemotherapy) was mapped in 2011 as 16.1km on average, with the North West electorate of Braddon sitting third of the five electorates. However, Braddon fared worst in travel to radiotherapy services, at 129.5km on average compared to the state average of 52.9km (Deloitte Access Economics 2011). Compared nationally, Tasmania fared fifth lowest out of eight states and territories for travel to infusion services and fourth for travel to radiotherapy. Such figures give a preliminary indication that Tasmania fares relatively well compared with geographically larger states and territories. Such a simple comparison of distance, however, does not give a full picture of the burden of travel. Distances were calculated on an 'as the crow flies' basis, meaning that road condition, topography and distance were not considered (Deloitte Access Economics 2011).

Weather conditions can exacerbate issues associated with rurality and therefore access. The Bass Strait Islands and Bruny Island are separated from mainland Tasmania by sea. Inclement weather can prevent air or water access by outlying islands of Tasmania, such as the Bass Strait Islands and Bruny Island and, consequently, delays can occur in providing ambulance transfer and medical retrieval. Strahan, Rosebery, Queenstown and St Marys can be cut off by road as a result of snow or landslides. St Helens can be cut off by road as a result of flooding (Department of Health and Human Services 2012d). Such problems are not considered in the measurement of distance to treatment, which also assumes that their relatively shorter distances to travel to services impose no burdens on the patient. When compared to the distances on geographically larger states, such as Western Australia and Queensland, Tasmania certainly fares better; however, patients are still often required to travel and be away from their homes for up to seven or eight hours per day of treatment (DLA Phillips Fox 2010). It is not the distance itself, but the capacity for the patient to travel to services with minimal or no burden, that is the just measure of their experience.



Such problems with distance mean that some patients are unwilling or unable to travel from their support networks for treatment, and make the decision to receive the level of treatment available in their local area even if it does not offer them the best chance of survival (Senate Community Affairs References Committee 2005). It is estimated that half of cancer patients in Australia are referred for radiotherapy, for instance, but that each year approximately 10,000 patients do not receive this treatment (Clinical Oncological Society of Australia 2006). In Tasmania the referral rate is only 42% (DLA Phillips Fox 2010). This highlights a discrepancy between those who could benefit from radiotherapy and those who actually access it. Certainly in Tasmania there is anecdotal evidence of this problem, especially on the North West coast (DLA Phillips Fox 2010; Parliamentary Standing Committee on Public Works 2012).

The alternative to travel is to have a greater array of services closer to home. However, these services are often less comprehensive and less appropriately staffed than those offered in major centres. When the Clinical Oncological Society of Australia (COSA) mapped current oncology services in Australia (2006), it found that 38% of rural hospitals that administered chemotherapy did not have a resident or visiting medical oncology service. It also found that only 7% of rural hospitals administering chemotherapy had access to a radiation unit, and that as remoteness increased patients were more likely to have chemotherapy administered by a general registered nurse rather than a chemotherapy-trained nurse. Of these same rural hospitals, 61% indicated that urgent access to psychological support services was required. There were no surgical oncologists in remote or very remote areas of Australia (Deloitte Access Economics 2011).

Such issues relating to access to radiotherapy services have not remained unacknowledged by policy-makers. The federal Department of Health and Ageing's Radiation Oncology Inquiry in 2002 stated that the travel and expenses borne by patients in accessing radiation therapy was 'inherently inconvenient', but was an unavoidable consequence of centralisation of services. This was a double disadvantage to the regional community: of living in regional or remote areas and of being diagnosed with cancer (Hegney et al. 2005). The completion of the North West Regional Cancer Centre, however, is unique in appearing to place the 'inconvenience' of travel by regional and remote patients above the 'unavoidable consequences' of centralisation.

## Snapshot of Cancer Services in Tasmania

Tasmania is the smallest state of Australia and is divided into three regions for the provision of health services (see Figure 3).



**Figure 3 Map of Tasmania**

Tasmania has the dubious honour of having the second highest incidence of cancer diagnosis in Australia, after Queensland, and the second high mortality rate, after Northern Territory (Australian Institute of Health and Welfare 2012b). Much of this can be attributed to Tasmania's high median age compared with the rest of Australia, leading to 20% more cases of cancer each year than if median were the same as the national median (Department of Health and Human Services 2013a). The Tasmanian health system is one of the most significant financial investments by the state, in partnership with the Commonwealth. In 2011–12, government funding of Tasmania's health system totalled \$2.193 billion, with a further \$988 million from private sources (Australian Institute of Health and Welfare 2013a). Within this is the provision of a system of cancer services, across the continuum from prevention to palliation. The current system of delivery services to cancer patients is the culmination of policy responses to this issue.

A typical pathway for a cancer patient will start with either a symptomatic visit to a GP, systematic screening such as BreastScreen, or surveillance of high risk individuals, such as

those with a genetic predisposition towards certain cancers, usually by their GP (Department of Health and Human Services 2012a). Examination, biopsy or imaging will result in a diagnosis and the GP will then refer the patient to an oncological surgeon who will connect the patient with a multi-disciplinary team. From there the patient will be referred to the treatment phase, involving any combination of surgery, chemotherapy, radiation therapy and palliation. Information needs are also identified, but there is no clear pathway defining whose responsibility it is to provide such information.

## State-wide Services

Cancer admissions are expected to rise at a rate of 2.6% per annum in Tasmania, from 8769 in 2007–08 to 12,634 by 2021–22 (DLA Phillips Fox 2010). There are three major referral centres for treatment and care of cancer patients: The Royal Hobart Hospital (RHH), Launceston General Hospital (LGH), and the North West Regional Hospital (NWRH) in Burnie (DLA Phillips Fox 2010). The three hospitals, in addition to the Mersey Community Hospital (MCH) in Latrobe, deliver acute cancer services (Department of Health and Human Services 2015b). Further services are offered by district hospitals, community health centres and multipurpose centres (MPCs).

The delineation of services was outlined in 2009 (Table 4).

**Table 4 Tasmanian Cancer Service role delineation 2009**

Service	Nature of Service
Single site, state-wide and interstate services	Highly specialised services, low-volume
Comprehensive cancer care centres	High-level care including surgery, medical oncology, haematology, radiation oncology and core cancer services (cancer care centres at LGH and RHH)
Sub-regional cancer services	Generally major health facilities, providing services for less complex cases, or contributing a specific component of care such as surgery or chemotherapy (private hospitals, NWRH)
Local community cancer services	May be a primary care facility providing basic cancer care, in-reach services, or access point for support services (MPCs and community hospitals)
Supportive services	Basic supportive care provided by GPs with or without the assistance of other services
Population-based services	Screening programs, primary health care, other community services, education and prevention programs

Source: (DLA Phillips Fox 2010)

Medical oncology/haematology services are mostly delivered out of Hobart and Launceston, with outreach to Burnie and Latrobe (DLA Phillips Fox 2010). Some smaller district hospitals administer some chemotherapy services. Surgical interventions are provided at RHH, LGH and NWRH, with some specialised surgeries delivered at single sites only. In-patient palliative beds are located at RHH, LGH and NWRH (North West Radiotherapy Clinical Expert Panel 2011).

Single site, state-wide cancer services include

- gynaecological oncology – RHH
- autologous bone marrow transplantation – RHH
- brachytherapy – LGH

- paediatric and adolescent oncology – RHH
- tumours of the central nervous system – RHH
- thoracic cancer surgery – RHH (DLA Phillips Fox 2010)

Some specialised tumours, rare and complex cancers, and some paediatric cancer services require interstate travel.

Services across the state are supported by informal and semi-formal mechanisms for interaction, such as outreach visits to the North West by southern- and northern-based specialists, monthly radiation oncology forums, joint clinics between medical and radiation oncologists, and state-wide specialist meetings (DLA Phillips Fox 2010). However, according to the Tasmanian *Cancer Framework and Strategic Cancer Plan*, this does not constitute a structural framework that allows for comprehensive and coherent integration into one state-wide service (DLA Phillips Fox 2010).

### *Southern-based services*

The W.P. Holman Clinic (RHH) is home to a comprehensive range of cancer services, including a twelve-chair/two-bed day oncology unit; two linear accelerators for the delivery of radiation therapy; multiple imaging tools including a CT, magnetic resonance imaging and PET (positron emission tomography) scanner; and extensive pathology services (North West Radiotherapy Clinical Expert Panel 2011). A \$586 million redevelopment of RHH in 2012 resulted in an additional bunker being added for a third future linear accelerator, as well as the inclusion of the PET scanner, 3D planning system and new ultrasound suites (Department of Health and Human Services 2012c); chemotherapy chair capacity was increased and a support centre included. In-patient services are provided in RHH's 20 bed oncology/haematology inpatient ward, supported by pathology services within the hospital (North West Radiotherapy Clinical Expert Panel 2011).

### *Northern-based services*

The W.P. Holman Clinic at LGH was initially established as a branch of the Peter MacCallum Clinic in Melbourne but was renamed after the man who established the first oncology medical practice in Launceston in 1925. It provides outpatient medical oncology, including

chemotherapy and diagnostics, radiation oncology and clinical haematology services (Department of Health and Human Services 2015c), supported by LGH's pathology services. The clinic's facilities include twelve chemotherapy chairs and one bed, three linear accelerators, state-wide provision of brachytherapy, and a CT simulator (Department of Health and Human Services 2015c). A third linear accelerator for the Launceston clinic was built after Commonwealth funding was committed as part of the 2006–07 federal budget and included a new bunker for the linear accelerator, extended treatment areas, a patient transit lounge and accommodation facilities (Department of Health and Human Services 2009a). The third linear accelerator was a recognition that demand for services in the North, including the North West as part of its catchment area, was increasing.

In-patient services are provided through a dedicated oncology ward at LGH; private services for chemotherapy are also offered at the St Luke's Campus in Launceston (Department of Health and Human Services 2007).

### ***North West services***

The North West region is unique in that it has two major public hospitals, NWRH and MCH, in addition to the North West Private Hospital in Burnie (NWPH), plus district hospitals at King Island, Smithton and the West Coast (Rural and Regional Health Australia 2012). The two major hospitals in the region are the most expensive hospitals to operate in the state (Department of Health and Human Services 2015b).

Until 2016 the North West offered a more limited range of cancer services than the Northern and Southern regions, and many services were accessed by outreach or travel by patients. As of 2011 it had nine chemotherapy chairs and one bed in the North West, general medical and surgical wards for in-patient needs at NWRH, and pathology services contracted to the private sector (North West Radiotherapy Clinical Expert Panel 2011).

A new magnetic resonance imaging facility, funded by Commonwealth and private funds, commenced operation at NWRH in 2013, providing much needed diagnostic services to cancer patients in the region (Tasmanian Health Organisation - North West 2014). As of 2012, NWRH had bi-weekly oncology and fortnightly radiation oncology outreach clinics (Rural and Regional Health Australia 2012). This scheme saw 228 patients access oncology

outreach services in 2009–10. Specialists not only saw patients during their outreach visits but continued to act as a liaison service outside those times. No parallel services were offered out of MCH. The scheme was brought about in recognition that recruitment into specialist health areas was problematic in regional Tasmania and that a lack of critical mass, as well as dispersal of the North West population, often made full-time specialist positions untenable (Rural and Regional Health Australia 2012).

The MCH offers a level 4 cancer service, which includes visiting oncology services and ambulatory chemotherapy (Department of Health and Human Services 2015b). The day service offers cancer treatment and management including education, support, outreach, referrals, chemotherapy, transfusion and infusion services, and IV access (Department of Health and Human Services n.d.-a).

NWRH transferred its oncology services to a purpose-built North West regional cancer centre in 2015. Oncology services were recommenced in this centre, and radiation therapy commenced in 2016 after the installation of the first linear accelerator in the North West region (Tasmanian Health Service 2016).

## Travel and accommodation

Travel by North West residents for cancer services is a complex and expensive issue for the Tasmanian health system, accounting for approximately 20% of all claims under the Patient Travel Assistance Scheme (PTAS) (Department of Health and Human Services 2015b). PTAS offers financial support to Tasmanian residents for transport and accommodation costs associated with attending treatment not available within their local area (Royal Hobart Hospital 2011). This can include public transport, per-kilometre private vehicle reimbursements and flights for residents of King Island or the Furneaux Islands, as well as contributions towards accommodation.

While there is a variety of commercially available accommodation near RHH and LGH, the John Opie Fight Cancer Foundation House in Hobart offers 14 rooms just above the PTAS rate specifically for cancer patients (Royal Hobart Hospital 2011). Launceston has similar accommodation options for any patient travelling for medical reasons (Launceston General Hospital 2012).

Additional transport options are available through the Cancer Council Tasmania's transport-2-treatment (t2t) program. It primarily operates a free transport service to treatment and appointments from Burnie and Devonport, with further assistance to get people to the pick-up points; it provided 4815 trips in 2013–14 (Cancer Council Tasmania 2014). The t2t program also offers reimbursements to family or friends who take patients to treatment, as well as assistance to patients who can drive themselves but are unable to meet the high cost of travel (Royal Hobart Hospital 2011).

Beyond transport assistance, Cancer Council Tasmania remains one of the most prominent support organisations for cancer patients and their families. Services include the provision of information, personal support programs, a wig library, Pilates classes, and informal social gatherings (Cancer Council Tasmania 2014). Despite its having created the Cancer Council to meet the need for patient and family support, the government expected the organisation to remain self-sufficient (Cancer Council Tasmania 2014): all the services offered are contingent on the fundraising capacity of the organisation.

### Cancer workforce

There are staff shortages in the areas of haemoncology and oncology throughout the state, a particularly entrenched issue for the North West. The North West continues to rely on visiting services from Launceston, Hobart and interstate for specialist access (DLA Phillips Fox 2010). The Tasmanian Government's Cancer Strategic Plan noted that when specialists are found for the North or North West, they often lack sufficient support staff such as trainees and care coordinators, and there is little or no succession planning. The Clinical Expert Panel, commissioned in 2011 to provide advice on the need for radiotherapy services in North West Tasmania, noted that the area has a high rate of GP turnover and of overseas-trained GPs. Both of these were highlighted as potentially decreasing a GP's understanding of and connectedness with cancer services and referral pathways (North West Radiotherapy Clinical Expert Panel 2011).

Nurses generally act as cancer care coordinators for newly diagnosed patients, and some community-based nursing roles have been introduced in recent years, including Breast Care nurses funded by the McGrath Foundation, bowel screen nurses, and nurses funded by the



Leukaemia Foundation (North West Radiotherapy Clinical Expert Panel 2011). There are no allied health professionals employed to work specifically in cancer services, and these services are therefore provided by the general allied health professionals in the public sector.

The most recent figures relating to Tasmania's cancer care workforce are from 2011; they will have altered significantly since the opening of the North West Regional Cancer Centre (see Table 5).

**Table 5 Tasmanian cancer workforce 2011**

	North	South	North West
<b>Medical Oncologists/ Haemoncologists</b>	3 FTE/ 3 FTE	5.0 FTE/ 2.0 FTE	Peter MacCallum Institute (Melbourne) visiting medical oncologist 8 days per month; visiting clinical trials oncologist from RHH 1 day a month; visiting medical oncologist from LGH 2 days per month; visiting haemoncologist from LGH 3.5 days per month
<b>Radiation Oncologists</b>	3 FTE (public/private combined practice)	3.0 FTE (2 combined, 1 public)	Visiting service from LGH 2 days per month
<b>Palliative Care Physicians</b>	2 FTE	3 FTE	1 FTE (vacant) with visiting service from RHH
<b>Registrar Training Positions</b>	1 accredited trainee in radiation oncology; 1 accredited advanced trainee in medical oncology	1 advanced trainee in medical oncology; 2 advanced trainees in haemoncology; 1 accredited trainee in radiation oncology	Nil (As of 2013 there was a part-time Registrar provided free of charge by the Peter MacCallum Institute) (Bingham 2013a)
<b>Cancer Care Coordinator</b>	1 FTE	1 FTE	Nil

(North West Radiotherapy Clinical Expert Panel 2011)

## Health as policy

North West Tasmania faces health challenges that stem from its regional and remote nature. The summary of the state of cancer services across Tasmania, according to the most recent information available, allows a fuller picture of how a North West radiation therapy service would fit with the overall network of services and how this might address regional health disparities. To further establish context for the development of a local radiation therapy service, it is important to explore health as a policy subset and to see how health has been treated politically in Tasmania since 2000.

It is generally fair to say that the health sector has specific characteristics, which affect the policy environment (and that differentiate it from other social sectors). The state may be both provider and purchaser of services, but also is involved in regulation, research and training ... In service provision, it may be in competition or partnership with a private sector that it is also regulating ... the state is usually heavily reliant on ... essential information that can only be provided by the sectors it is over-seeing ... Health issues are often high profile and demand public responses. Health interests, ranging from professionals to the pharmaceutical industry, have traditionally been perceived to influence the policy process significantly. They are uniquely placed to do so because of their knowledge, technology, access to political processes and stake in life and death issues. (Walt et al. 2008, 308-309)

Provision of a public good underpins all public policy. Health policy is meant to pave the way from the intent to meet a public good to the provision of those public services that meet societal expectations. However, the reality is that the development and implementation of public policy is a complex process, shaped by competing interests, power imbalances, political opportunism, and public expectations. The usual result, a policy that attempts to meet the needs of stakeholders, the demands of interest groups, the expectations of society and the realities of fiscal constraint, is often far from ideal, with both intended and unintended consequences for end users.

Health policy, specifically, embraces intended courses of action designed to affect the series of institutions that make up health care, and may be shaped by, and include, both state policies and the commitments of political parties that may subsequently form government (Palmer & Short 2014). These public policies sit alongside, and may work in conjunction with or in opposition to, the policies of private and non-government health organisations.

The development of health care policy in Australia is affected by the complex interactions between individual states and the Commonwealth, and requires a consideration of the concept of power in shaping policy, particularly as it applies to the medical profession; of public perceptions of health, of health rights and accessibility; of the nature of political opportunism and the election cycle; and of the imbalance between health care policies aimed at the acute sector and those developed for preventative and public health.

### State/Federal Health Policy

In health, a government can be service provider, purchaser, regulator or administrator, giving it often-conflicting roles (Walt et al. 2008). Health care is funded, delivered and managed at both state and federal levels, allowing the possibility of cost-shifting, blame-laying and political manoeuvring (Palmer & Short 2014). Under the Australian constitution the federal government has limited legislative powers and no stated power in regard to the provision of health services; however, it has the ability to exert power over the health agenda of individual states and territories, derived from its exclusive power to collect income taxes, customs and excises duties (Scully 2009) and contributes to the blame game.

Government funding accounted for 69.7% of total health expenditure in 2011–12, with the federal government providing 42.4% of total health expenditure (Australian Institute of Health and Welfare 2014a). Hospitals and primary health care accounted for the largest slice of the funding pie: 38.2% and 36.1% respectively (Australian Institute of Health and Welfare 2014a). States are responsible for determining the location and mix of acute hospital services, while the Commonwealth provides medical benefits to patients outside the acute public system, namely the private sector and general practice (Palmer & Short 2014). This creates the potential for health service policies that shift patients between different services to maximise savings. Such was the extent of cost-shifting in the recent past that the National

Health Reform Agreement (2011) explicitly included mechanisms of oversight to ensure that one party did not alter the terms of management and administration to shift services and therefore costs from the community sector (largely a Commonwealth responsibility) to the hospital sector (states and territories), or vice versa. This was the result of continual debate about equity in Commonwealth health funding to states and a decreasing proportion of Commonwealth contributions to state contributions (Australian Institute of Health and Welfare 2013a).

Such conflict gave rise to many political statements of intent to ‘end the blame game’ in health service provision, culminating in efforts by Rudd’s Labor government to initiate discussions on a full federal takeover of funding and responsibility for health care (Palmer & Short 2014). The National Health Strategy of 1991 drew on considerable evidence on the mixed and inconsistent division of responsibility for health care, and the final report of the Rudd-initiated National Health and Hospitals Reform Commission in 2009 called for clearer divisions of responsibility for funding and the provision of services (Palmer & Short 2014). So far the recommendations of neither the Strategy nor the Commission have led to any substantive change to the division of such responsibilities (Palmer & Short 2014).

State and federal relations in reference to cancer services exist along a continuum of prevention, education, detection, treatment and palliation, and encompass primary, secondary and tertiary health services. Both states and Commonwealth are responsible for cancer services, and their respective policies can have an impact on accessibility and delivery.

## Power

Although all actors in a policy debate seek to exert influence over the outcomes, their capacity to do so depends upon their perceived or actual power (Palmer & Short 2014). Power can take the form of financial resources, persuasive personality, skills and knowledge, authority or networks (Buse, Mays & Walt 2012), and can be exerted to control how an issue is framed, what form the policy takes, how it is implemented and evaluated—and even if it makes it onto the policy agenda. Lukes’ (2005) discussion of the three dimensions of power presents power as taking the form of decision-making (the overt acts of those with power to

influence decisions), of non-decision-making (limiting the scope of decisions to those deemed safe or acceptable by the more powerful actors), and thought control (shaping the views and opinions of other actors to align with their own, often through subtle means). Buse, Mays and Walt (2012) view this last as the most insidious form of power, as it never allows the other actors to understand their own views or possible objections.

Knowledge and expertise act as a kind of policy 'currency' that can filter information entering the policy processes and affect the way an issue is perceived and addressed. With their stronghold over knowledge, technical skills and material resources, and their high sense of legitimacy, the medical profession, who have no equivalent in most other policy areas, can disproportionately affect the health policy agenda (Walt et al. 2008). The technical skill of medical doctors endows them with such authority that patients rarely question their advice in health care matters. The pharmaceutical industry, although perhaps wielding less authority, has the financial capacity to fund think tanks, advocacy groups, research bodies and public relations campaigns to shape public opinion (Buse, Mays & Walt 2012). Adams (2004) calls this form of policy discourse 'gatekeeping'.

Much of the twentieth century saw doctors regulate and control their own training and occupy a dominant position in health policy development, and the resulting health care system was one of deference to the medical profession (Buse, Mays & Walt 2012). While this has changed somewhat with the introduction of some budget caps, increased consumer awareness and the professionalisation of other health practitioners such as nurses, the power imbalance still remains (Buse, Mays & Walt 2012).

As Buse, Mays and Walt (2012) and Palmer and Short (2014) agree, health reform comes at the expense of the status quo, which is often upheld and protected by the more powerful and well organised groups such as the medical and pharmaceutical sectors. This ultimately makes change difficult to achieve and puts the medical profession at loggerheads with corporate rationalisers (Palmer & Short 2014). Knowing this, where does this leave vulnerable cancer patients? As individuals they are unable to wield the same level of power and influence, although they are the end users of cancer services and subject to the policies that define them. Public advocacy groups are vital in giving a voice to patients and their

families, in the hope they may add another perspective and ground the debate in practicalities amidst these identified power imbalances.

Power is an important concept to understand in relation to cancer services as the design of public policy for delivery, and accessibility of such services, may be shaped by forces other than neutral and impartial decision-making. To understand these forces is to begin to understand the subsequent policy.

## Public Interests

Health care is a policy issue that stretches across all sectors of society. Regardless of socioeconomic status, geographic location, health status, political persuasion, disability, occupation, education or ethnicity, there is an expectation that every member of society will be able to access an acceptable standard of health care. Sindall (2003) describes health policy as a series of distributive decisions across society; it is therefore a contributor to and indicator of social justice. As the sole aim of health care policy is to improve the health status of the general public, this creates a need, and indeed an expectation, that any reform or creation of policy will be able to be understood by the general public, and that they will have reasonable access to inclusion in the policy process (Maluleke 2010).

Community participation, through advocacy, education and consultation, has been encouraged through various means by various governments, from the Community Health Program of the 1970s through to recent district health forums in Tasmania (Palmer & Short 2014). The advantage of community participation is that participation and interest can equate to increased knowledge about health issues and alter health-related behaviours.

However, political response to community demands needs to be viewed in perspective with the power imbalances discussed earlier. Health policy can result in both policy outputs and policy outcomes. While outputs include what governments actually do, and can be reasonably predicted and measured, outcomes, such as improvements to health in the target population, are less readily predicted and measured (Palmer & Short 2014). This is important, as value derived from the policy will only be perceived by the public if they see or experience an improvement in health status.

Although the report from the 1992 National Health Strategy (Palmer & Short 2014) found that health care was reasonably accessible to all Australians, 25 years later the reality remains that those from lower socioeconomic backgrounds, and rural and regional locations, experience inequalities in accessing health services. Given the geographically dispersed population of Australia, the delivery of health services and improvement in health equity creates a logistical and economic problem for policy-makers, especially the secondary and tertiary services that remain largely the domain of urbanised areas (Palmer & Short 2014).

The notion of public interest in health care is very relevant to cancer services as Tasmania in particular has a highly regionalised population and a comparatively lower socioeconomic status. This creates a need for and expectation of receiving necessary services in the Tasmanian population, but the reality is that access is limited.

## Public Health

Health promotion is a striking example of a policy that is not often implemented because it may work counter to the economic interests of powerful groups. (Palmer & Short 2014, 268)

Public health rests on the premise that health outcomes are often less closely linked to health services than they are to social, environmental, economic and lifestyle factors (Palmer & Short 2014). With lifestyle risks accounting for 32% of the total burden of disease (Australian Institute of Health and Welfare 2012a), it would seem logical that funding would aim to promote good health and prevent such risk factors, rather than treating their consequences. The burden of disease in Australia, which is largely attributable to cancer and cardiovascular disease, can be linked to 14 risk factors, almost all of which are preventable, such as tobacco use, daily activity and vegetable and fruit consumption (Australian Institute of Health and Welfare 2012a).

Such lifestyle factors require a change in public perceptions rather than the curative elements of health care. However, changing perceptions can be more difficult and slower to achieve than treatment options, which are often perceived as more directly linked to cause and effect. In reality, many treatments are subject to the law of diminishing returns, with



increased resources not necessarily resulting in corresponding increases in health (Palmer & Short 2014).

The establishment of community health centres in the 1970s is a prime example of historical moves to provide public health services aimed at prevention and health education, a move that interestingly saw strong opposition from the medical profession at time (Palmer & Short 2014). Funding for community health has waxed and waned since then, with the most recent National Health and Hospitals Reform Commission Report (2009) once again recommending the creation of multi-disciplinary health centres and Commonwealth responsibility for all primary health (Palmer & Short 2014).

The need to change our focus from treatment to prevention appears regularly in policy discussion. Despite this, health expenditure is still very focused on the acute sector, despite continued rhetoric around the importance of health promotion, prevention and primary health care. While the Tasmanian Minister for Health stated that health care reform needs a greater focus on promotion and prevention (Department of Health and Human Services 2015a) and the Department of Health and Human Services espoused a 'healthy public policy approach' (2013a), the reality is that only 1.7% of health spending is on public health, compared to 31.2% on public hospital services (Australian Institute of Health and Welfare 2012a). This creates a clear distinction between the perceived importance of public health and the reality of its translation into policy.

Compounding the issue, the health care profession is ineffectually designed to promote good health. With funding structures keeping medical practitioners focused on diagnosis and treatment, and financial incentives moving them towards specialised, treatment-related fields, there is little incentive for them to focus on promotion and prevention (Palmer & Short 2014). The result is continued pressure on acute services to treat causes of ill health, but little more than a history of report and declarations on the need to treat the 'causes of the causes' (Keleher & MacDougall 2016). Given the strong link between lifestyle risk factors and some cancers, Tasmania's high incidence of these risk factors, and the potential impact of prevention and education on cancer prevalence, it is clear that an analysis of primary health policy has a bearing on cancer-related public policy in Tasmania.

## Health Reform in Tasmania

Inquiries and plans to changes the Tasmanian health care system have been a cornerstone of the Tasmanian political landscape. Over the last 15 years there have been no fewer than six proposals to alter the system, with varying degrees of success and implementation. These reforms are summarised in Table 6 (below).

**Table 6 Tasmanian health reforms 2000 onwards**

Plan/Report	Year	Key Proposals	Success of Implementation
The Richardson Review (Expert Advisory Group 2004)	2004	Develop clinical service frameworks  Develop dedicated service centres  Expanded options for rural and regional treatment of chronic conditions  Consider a single hospital in the North West (NWRH) with emergency and ambulance at MCH	Negative public response to the Issues Paper and an announcement by the operator of MCH of restrictions to emergency and obstetric services resulted in a \$75 million commitment to improving hospital sustainability, including a further \$16 million commitment to the government resuming management of MCH (Shannon 2005).
Tasmania's Health Plan (Department of Health and Human Services 2007)	2007	Establish clinical networks to advise on policy, planning, training and governance  A new 4-tier service model resulting in the downgrading of hospitals at St Mary's, Ouse and Rosebery to community health centres  Moving all high-acuity patients from MCH to NWRH  Closing the Department of Emergency Medicine at MCH	Strong community concern voiced over the reduction in services in local areas led to calls for more funding for beds rather than rationalisation of services.  The federal government purchased MCH from the state government in August 2007 as part of the federal election campaign.  Federal government also pledged to look into further funding for Ouse and Rosebery, but they were not re-elected.  In May 2008 a local mining employer on

		and creating an emergency care centre for stabilisation prior to transport	the West Coast entered into an agreement to provide a contribution to the funding of the Rosebery Community Health Service (Shannon 2010).
National Health Reform Agreement (Council of Australian Governments 2011)	2011	Move to activity-based funding, resulting in some change to services  Introduction of three regionally-based health organisations to increase local decision-making and greater clinical engagement (Parliament of Tasmania 2011)	3 vs 1 health organisations in Tasmania became a point of differentiation between the state government and Liberal opposition. 3 Tasmanian Health Organisations were merged into 1 Tasmanian Health Service after the Liberals came into power (Department of Health and Human Services n.d.-b)
Commission on Delivery of Health Services in Tasmania (Commission on Delivery of Health Services in Tasmania 2014)	2014	Created as part of the \$325m Tasmanian Health Assistance Package to identify structural and systemic improvements (Commission on Delivery of Health Services in Tasmania 2012a)  Final Report makes a range of proposals around governance, consumer engagement, efficiencies and culture  Recommends a halt to RHH redevelopment	There were changes in both state and federal governments prior to the release of the report.  Findings in the report were used as a precursor for the One Health System's proposed reforms (Department of Health and Human Services 2014b).
One Health System (Department of	2015	Creation of the Role Delineation Framework for a Clinical Services Profile	The White Paper was released in June 2015; implementation is ongoing

Health and Human Services 2015b)	<p>Centralisation of some services, such as a dedicated day surgery centre at MCH, and North West maternity services at NWPH</p> <p>Linking NWRCC into the Northern Integrated Cancer Service and sharing staffing resources with the North</p>
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## Tasmania's Strategic Cancer Framework

Tasmania's cancer services are underpinned by the strategic document *Cancer Framework and Strategic Cancer Plan 2010–2013* and expresses the vision of the DHHS's *Strategic Directions 09–12* (DLA Phillips Fox 2010). The plan is yet to be superseded. It outlines the current design and structure of services in Tasmania, and creates objectives for achieving the best outcome possible for cancer patients. The objectives include creating an integrated and sustainable system through clear service delineation, building the capacity of the cancer centres at RHH and LGH, improving workforce recruitment and retention, and acknowledging the need to build services and partnerships in the North West. The plan explicitly states that 'there is a need to improve access to services across the continuum of care, including prevention, screening, diagnosis and treatment, particularly for residents of the North and North West of Tasmania and rural residents generally' (DLA Phillips Fox 2010, 23).

### *One health system*

In the first half of their first term, the new Tasmanian Liberal government proposed a review of Tasmania's health system: the *One State, One Health System, Better Outcomes* (OHS) 2015 reform package, initiated in response to Tasmania's lower than average life expectancies, higher levels of chronic disease, and high rates of adverse events within hospitals (Department of Health and Human Services 2014a). Reforms began with a Green

Paper, Role Delineation Framework, public submissions, an Exposure Draft, further consultations and submissions, and a final White Paper.

Much of the change proposed by the OHS White Paper mirrors that suggested by the Richardson Review and Tasmania's Health Plan, in particular the state-wide provision of services rather than providing as many services as possible in local facilities, in order to maximise efficiencies, patient safety and service sustainability.

Service changes proposed in the White Paper include:

- establishing MCH as a dedicated elective surgery facility for the state
- closing the MCH high dependency unit and medical ward
- creating a drug and alcohol Level 4 service at MCH
- consolidating all maternity services to NWRH in Burnie for North West patients (removing the MCH service)
- limiting MCH to Level 3 emergency services and transferring patients in a serious condition directly to NWRH or LGH
- limiting NWRH to Level 4 surgeries (low and moderate complexity)
- providing greater outreach services from Launceston to the North West, to reduce travel by patients to Launceston
- Investing \$24 million in patient and family transport and accommodation services to meet increased demand
- developing a Northern Integrated Cancer Service to deliver oncology services across the North and North West, managed from Launceston with sites at LGH and NWRH (NWRCC)
- providing a Level 5 medical and radiation oncology service for NWRCC (moderate to high complexity inpatient services)
- providing a Level 4 haematology service for NWRCC (moderate complexity)
- continuing Level 4 medical oncology and haematology services for MCH (visiting oncologists and specialised day treatments)
- commissioning the linear accelerator for NWRCC, with shared staff delivering radiotherapy services across the Northern Integrated Cancer Service to avoid a stand-

alone service in the North West and addressing the issues of safety and sustainability identified in the Clinical Expert Panel Report (Department of Health and Human Services 2015b).

In terms of specific changes to the provision of cancer services in North West Tasmania, the White Paper largely confirmed what had already been envisioned for the North West Regional Cancer Centre (see section below). The commitment to operational funding for NWRCC was prior to the release of the White Paper, and the linear accelerator was formally commissioned. Oncology service levels for MCH remained unchanged.

### The North West Regional Cancer Centre

The North West region of Tasmania is home to 22% of the total population (Tasmanian Health Organisation - North West 2014). In this region the incidence of cancer is projected to nearly double between 2011–21, to 1066 cases (North West Radiotherapy Clinical Expert Panel 2011). This means that while the population is widely dispersed throughout the region, demand is large enough for benefit to be gained by the provision of a radiation therapy service in one of the larger centres (DLA Phillips Fox 2010).

A population base of 600,000 is considered the core requirement for the establishment of a radiotherapy centre (Clinical Oncological Society of Australia 2006). However, consideration of the needs of the local community was required, especially given Tasmania's island status. Therefore three cancer centres were built – one in Hobart, one in Launceston and the newest in Burnie – in a state with approximately 500,000 residents.

A sufficient caseload for a radiotherapy service is 400 new courses per year, comprising 330 new cases and 70 retreatments (North West Radiotherapy Clinical Expert Panel 2011). As 377 patients from the North West had started radiotherapy in 2010, demand was already within this range (North West Radiotherapy Clinical Expert Panel 2011).

The North West Regional Cancer Centre, which brought radiotherapy services to the region, was the culmination of a prolonged debate within the local and political communities. An examination of the chronological history of this debate provides perspective on how and why the centre was finally funded and built.

## **2007**

As part of the 2007 federal election campaign, then opposition Leader Kevin Rudd and the ALP incumbent in the North West Tasmanian seat of Braddon, pledged \$7.7 million for a linear accelerator in Northern Tasmania (Australia 2010). The Liberal Party contended that this was a pledge for a linear accelerator in the North West (Abbott 2010). The member for Braddon argued that the commitment had been made with a preference for the linear accelerator to be in the North West, but that the region had not been in a position to provide radiotherapy services without significant further investment so a decision had been made to add a third linear accelerator to the Launceston centre (Australia 2010). The member himself called this a 'broken promise' (Australia 2010, 2437).

## **2009**

In 2009 the federal government launched the \$5 billion Health and Hospitals Fund (HHF), designed to invest in major health infrastructure (Department of Health n.d.). Round two of the fund included \$1.3 billion to establish 21 regional cancer centres to improve access and support for cancer patients in rural and regional areas. This was intended to address discrepancies in cancer outcomes for regional patients compared to their metropolitan counterparts. However, Coory et al. (2013) found that the only evidence on the effectiveness of such regional cancer centres is that patients who otherwise would have had to travel for radiotherapy could now be treated closer to home, and that this provided no insight into the benefits to quality of life and survival delivered by these centres. Questions were raised about the cost-effectiveness of such centres in comparison to other services such as transportation and accommodation.

A further three centres were funded under the HHF in subsequent rounds, and two under non-HHF funding. This fund would come to include the establishment of a cancer centre in Burnie.

## **2010**

As Australia headed into a federal election campaign in mid-2010, debate in North West Tasmania turned again to the provision of radiotherapy services. There was speculation that both major parties supported a radiation therapy service in the North West, prompting the Australian Medical Association Tasmania (AMA Tas) to publicly state that any expansion should not include a linear accelerator (Australian Medical Association Tasmania 2010c). The

chief concerns of AMA TAS were the recruitment and retention of the specialised oncology staff required to operate a linear accelerator, and the lack of precedent for operating a single-unit facility in a population of only 100,000: the association noted the failure of single-unit facilities in Victoria to operate effectively in populations of 250,000, and expressed concern over the poorer subsequent clinical outcomes for patients.

Discussion turned to why the region did not yet have radiotherapy services, and accusations and blame circulated as part of the election campaign. The Liberal opposition pointed to the ALP's broken 2007 election promises. The Gillard government stated that Tasmania did not have radiotherapy services in the North West because the state government had not applied for funding for such a service (News.com.au 2010). The state government said that they had promised only extended cancer services in the near future, not radiotherapy services; Treasury documents showed that the state government had promised a linear accelerator for Burnie at the state election of 2010 but had not specified a timeline for its installation (Livingston 2010). The original policy costing, sent to Treasury by then Premier David Bartlett in February 2010, proposed \$10 million to 'fast-track' cancer services in the North West.

Debate in the community increased during the federal election campaign in July and August of 2010. On 8 August a community forum held in Burnie was attended by over 200 residents, community leaders and politicians (ABC News 2010a). At it the state government stated that a clinical expert panel would be formed to examine the feasibility of establishing radiotherapy services in North West Tasmania; and that if the panel supported the service, and if committed federal funds were received for the infrastructure, the state government would fund the operation of the service (Tasmania 2011).

On the eve of the public meeting the federal opposition committed \$7 million of a new \$85 million fund for a linear accelerator in Burnie, the first project to be funded under the new scheme (Abbott 2010). The opposition leader, Tony Abbott, proposed that the linear accelerator would be online by 2013. The federal Health Minister responded by committing \$16.5 million specifically for a linear accelerator and associated infrastructure in Burnie (Australia 2011). The state Liberal opposition immediately rebuffed this commitment as inadequate in comparison to other regional areas, citing regional cancer funding of \$70



million for Townsville, \$42 million for Ballarat, and \$31 million each for Tamworth and Armidale (Tasmania 2010c).

AMA Tas reiterated its concerns and proposed caution until a feasibility study was done, and stated that a linear accelerator in North West Tasmania failed two criteria: safety and sustainability (Australian Medical Association Tasmania 2010b). Providing a safe and sustainable service would require staffing, transport, accommodation and support services that reached beyond the current funding commitments. The organisation continued to express these concerns via media into 2011 (Dolan 2011).

### **2011**

Although the funding commitment had come from the Federal Government as part of a Federal election campaign, the actual decision-making body that would make the final recommendation to build a local radiation therapy service was in fact the State Government. Health remains a state responsibility and as such the funding commitment was one that would simply be transferred from the federal coffers to the state, with no direct federal control over the final decision to build the service. This was despite that fact that both the federal and state governments of the time were of the same political persuasion. In Tasmania, decisions are made by referring legislation to the Lower House (House of Assembly) and Upper House (Legislative Council). In order to provide scope for such a decision, a report into a local radiation therapy service was commissioned by the State Government.

The Clinical Expert Panel Report commissioned by the Tasmanian Minister for Health found comprehensively that there was sufficient present demand for one linear accelerator in the North West (North West Radiotherapy Clinical Expert Panel 2011). Demand was deemed to derive not only from the projected rise in incidence, but also from the distances and duration of travel for patients. A typical return journey to Launceston for treatment or appointments is 300km (depending on location), and a course of radiation therapy can typically last up to eight weeks. The chief radiation oncologist voiced concern over the distances North West patients needed to travel for treatment to ABC News, highlighting the harsh effects of chemotherapy and radiation therapy that are exacerbated by long travel times (Bevis 2014).

With only 42.5% of new cancer cases in the North West accessing radiotherapy, the region falls short of the national benchmark of 52%; and there was anecdotal evidence that some patients from the region chose to delay or forego radiotherapy because of distance (North West Radiotherapy Clinical Expert Panel 2011). A medical oncologist with the then-North West Area Health Service, stated in 2012 that she had patients who had discontinued treatment because of the burden of travel and illness it entailed (Parliamentary Standing Committee on Public Works 2012).

When considering the potential impacts of the proposed radiotherapy service in Burnie, the Clinical Expert Panel Report noted that there would be no guarantee that specialists would refer patients to the regional unit, and that this might lead to under-utilisation of an expensive service (North West Radiotherapy Clinical Expert Panel 2011). This poses an interesting question of why oncology specialists might choose not to refer a North West patient to a North West-based service.

Construction appeared certain upon receipt of the Clinical Expert Panel Report, as this had been the final requirement for the HHF to approve the committed funds, and it had been flagged by the state government at the community meeting the preceding year as the lynchpin for operational funding. However, in September 2011 the then Tasmanian Health Minister, Michelle O’Byrne, told ABC News that the money for operating the new centre could no longer be found and would not be able to be provided until 2015–16 (Tasmania 2011). Legislative Council member Ruth Forrest, in Budget Estimates earlier the same year, had asked the Minister for Health about this funding and the Minister had replied that the funding had been ‘quarantined’ within Treasury (Tasmania 2011).

## **2012**

In 2012 the Parliamentary Standing Committee on Public Works made its final recommendations to the Tasmanian Parliament on the North West Regional Cancer Centre (Parliamentary Standing Committee on Public Works 2012). The report highlighted the planned services of the facility as including twelve chemotherapy chairs, two paediatric wings, magnetic resonance imaging facilities, teaching and clinical trial facilities, consulting rooms, a linear accelerator bunker and control room, a second spare bunker and additional spaces. The centre was to be built with funds committed from the HHF, \$7.91 million from

the Tasmanian government, \$1.06 million in special purpose payments and a \$2.75 million donation from local entrepreneur Dale Elphinstone (Parliamentary Standing Committee on Public Works 2012). The private donation was specifically for a magnetic resonance imaging facility plus bonded scholarships to support radiation therapy students through their studies.

The committee had heard evidence that the Holman Clinic at LGH was running at capacity and had substantial waiting lists. Modelling indicated that a fourth bunker would be required by 2016 (Parliamentary Standing Committee on Public Works 2012). Crowding of chemotherapy chairs was also noted as a concern. The conclusion of the committee was that a comprehensive cancer care facility was needed in the North West, and thus NWRCC was given clearance to proceed.

### **2013**

Construction of NWRCC commenced in early 2013, with completion forecast as 2015 but services not expected to commence until 2016 (Bingham 2013a). No commitment for operational costs were finalised, and estimates were that \$3.5 million would be required to operate the facility when it opened. Discussions of how to staff the centre began to intensify in the media (Bingham 2013a).

### **2014**

The operational model for the centre was agreed in 2014, with NWRCC specialists earmarked to work between both Burnie and the Holman Clinic in Launceston (Bingham 2014b). This was seen as a way of addressing the lack of critical mass in the North West and allow clinicians to be recruited. Staffing was expected to be furthered aided by the bonded scholarships, which would see recipients in their final years of study by the time services commenced in 2016. Recipients were required to work in Burnie for a minimum of two years after registration (Bingham 2014b).

Operational funding was still to be finalised. A subsequent state election in 2010 resulted in a change of government. The new Liberal deputy premier, Jeremy Rockliff, stated that funding would be found for the centre's operation (Bevis 2014).

### **2015**

Operational funding was finally committed in the Tasmanian Budget 2015–16. The commitment of \$14.5 million over four years provided ongoing funding and came on the eve

of a white paper that proposed extensive changes to the current Tasmanian health care system (Ferguson 2015).

On 14 November a linear accelerator was installed into the new North West Regional Cancer Centre (Tasmanian Health Service 2016). On 18 December medical oncology moved from its previous location in the North West Regional Hospital and began operation at the new Centre (Tasmanian Health Service 2016).

## **2016**

The North West Regional Cancer Centre was officially opened on 6 May. Radiation therapy services commenced on 4 May, with two to three patients treated each day (Tasmanian Health Service 2016). This increased to 28 patients daily by June, providing an estimated 7500 annual patient visits in Burnie that otherwise would have been provided in Launceston.

## **Tasmania's Unique Political Context**

'The power of the relationship between a community and its hospital cannot be underestimated. Proposals for change can engender extreme community concern' (Department of Health and Human Services 2012d, 4). When considering how North West Tasmania came to have the cancer services that it does, including a substantial funding commitment for radiation therapy services at a time of economic austerity, one must consider the unique context of Tasmania, its people and its history. These factors blend to make a politically distinct climate for health care reform.

The aged and aging population of Tasmania presents unique challenges for the state in terms of the design of and demands on the public health care system, coupled with the state's growing inability to fund core services. Estimates point to Tasmania's health costs swallowing the state's total budget by 2022 (Eccleston 2013). This is also partly because the highly dispersed population has required a patchwork of rural health and hospital services across the state. Hospitals are traditionally linked to regions and regional culture (Shannon 2005). The services that usually emerge from this regional base enjoy a high level of support from their communities, in fund-raising, volunteer auxiliaries, donations—like that of Dale Elphinstone for magnetic resonance imaging facility and scholarships in Burnie (Bingham 2014b)—and active political lobbying at times of threat. However, the scattered services in

Tasmania struggle to achieve economies of scale, to maintain adequate staffing, and to provide the clinical volume needed for medical professionals to maintain necessary skill levels (Department of Health and Human Services 2012d). The majority of complex acute services, affiliated university programs, Health Department offices and health associations are based in Hobart, keeping most of the skill mix and staffing in the South. Shannon (2010) points to a pattern of funding such services based on history and geography rather than the changing needs of the community.

The basis for such funding and regionalised service delivery can be reasonably linked to Tasmania's unique system of voting and the effect this has on candidates and political machinations (Shannon 2009). Tasmanian candidates tend to be well known members of their local communities, either through business or volunteerism, or are local identities or from political dynasties, and it is the personal knowledge voters have of them that can lead a candidate to success (ABC News 2010b). The Hare Clark system used in state voting means that candidates compete in multi-seat electorates not just against other political parties but also against candidates from their own party. The absence of formal preference deals between parties and a ban on handing out 'how to vote' cards on election day means that candidates compete against all other candidates (Green 2006). This can make candidates more responsive to issues of local importance, as Shannon (2009) notes, including many communities' sense of isolation from services only found in major centres, and a strong sense of protection for the services provided locally.

The resistance by local Tasmanian communities to proposed changes and the willingness of governments and candidates to acquiesce is reflected in the numerous failed or partially implemented health reform plans. The 2007 Tasmanian Health Plan proposed sweeping changes to the health system to address a 'clear mismatch between our current services and the needs of the community' and to achieve 'safe and sustainable services' (Department of Health and Human Services 2009b, 6). These changes were publicised to local communities to facilitate understanding, consultation and support. The opposite effect was achieved, with knowledge of the planned changes mobilising communities against many of the changes, and the cost of delivering some of the ensuing commitments actually increasing overall costs, such as the repurposing of the hospital at Ouse (Department of Health and Human Services 2012d).

The outcome was much the same after the 2003 Richardson Review, seen by the local community as a government ploy to close the Mersey Hospital (Shannon 2005). The health community had achieved a high degree of consensus over the need to rationalise services in North West Tasmania to achieve safety and quality of care, and the information it provided was so convincing that the government, as the key policy broker, proposed to implement the changes in the Richardson Review. However, resistance to the rationalisation of services was strong, even in the face of technical, expert information on the need for change and consensus: an outcome acknowledged by the ACF as a reality when the failure of technical information to change the views of opposing coalitions affects policy by altering the views of policy brokers or government officials (Sabatier & Jenkins-Smith 1993a). Such resistance can be attributed to what has been called ‘an intimate tie between a service, its community support and its sustainability’ (Department of Health and Human Services 2012d).

Even when sustainability is questioned, change cannot easily occur in the face of overwhelming community support for a present service. Instead, governments and candidates engage in populist rhetoric and interventionist solutions in their election campaigns to invoke a sense of action. Such was the Commonwealth takeover of the Mersey Community Hospital in a key marginal seat during a federal election—a move that, although not discussed with key stakeholders or the local community beforehand, was well received by residents who had feared the loss of the service (Grube 2010). The takeover was the brainchild of the local Liberal incumbent, who looked set to lose his seat at the 2007 federal election (McCall 2010). The intervention met scepticism from the federal Department of Health, local leaders and the state government, but created a unique opportunity to distinguish the Liberals’ action from their opposition.

And so lies the disjoint between policy-making and political manoeuvring. Policy-making is no longer—if ever it was—an objective, rational, evidence-based weighing of policy alternatives. Rather, it is an activity occurring in a dynamic environment in which policy objectives and raw data are confronted by political necessity, electoral timeframes, media intrusions and ministerial gatekeepers (Grube 2010, 562).

Given multi-party commitments to fund a radiotherapy service in North West Tasmania as part of the 2010 federal election during a time of economic constraint, the resulting North

West Regional Cancer Centre could reasonably be considered in the category of political promises made to capture the 'politics of place' (Crowley 2000). A key marginal seat was at stake and an issue of seemingly local concern was identified as having possible currency with voters.

## Policy-making Process

To effectively analyse this policy decision it is important to understand the nature of policy development and to select an analytical theory or framework to aid analysis. Frameworks and theories allow a consistent and method by which to analyse policy decisions, and can serve to strengthen or further develop them. Prior to any analysis of the use of theoretical frameworks in examining health policy, it is important to first understand the nature of the policy process, which is described as a cycle with distinct and repeated phases.

### The Policy Cycle

It is logically impossible to understand any reasonably complicated situation—including almost any policy process—without some theoretical lens ... distinguishing between the set of potentially important variables and causal relationships and those that can be safely ignored. (Sabatier & Jenkins-Smith 1993b, xi)

When Maddison and Denniss (2009) define policy as a purposive course of action followed by an actor or actors, they give the impression that policy travelled an intended course. However, policy can be the culmination of multiple decisions, or non-decisions, made both transparently or otherwise over an extended period, with each decision spurred and shaped by different factors. Furthermore, policies can result in unintended consequences, moulded by the complex and often counter-intuitive nature of the policy environment (Maluleke 2010).

Althaus et al. (2007) argue that the sense of order created by a policy cycle model leads to good routine and role definition. Such a model, a cyclical path of problem identification, agenda-setting, formulation of a policy response, implementation, and an evaluative mechanism for policy improvement and redesign, is discussed and supported across much

policy analysis literature (Buse, Mays & Walt 2012; Cairney 2012; Maddison & Denniss 2009; Maluleke 2010; Palmer & Short 2014). Althaus et al. agree that there are many versions of a policy cycle, all of which rest on a premise of systematic thinking; and while it has its limitations and does not provide casual explanations, it offers a good descriptive basis for action (Althaus, Bridgman & Davis 2007).

Policy agendas are set when issues find the right combination of attention and political will. Althaus et al. (2007) believe that issues get onto policy agendas when there is agreement on the problem, the prospect of a solution, appropriate levels of government expenditure required, and a sufficient number of people who will be affected. Kingdon (1984) believes that issues reach the agenda when the problem stream, policy stream and political stream combine to give clear problem definition, technical feasibility, compatibility with societal values and capacity for consensus.

While some policy issues are ongoing, others only make it to the policy platform with a 'window of opportunity', created when the issue moves from being of interest to a select few to 'crisis' status among the general public (Palmer & Short 2014). Howlett discusses windows of opportunity and demonstrates how most are the result of routine, institutionalised processes and can therefore be approached with some certainty (1998). An issue such as the one discussed in this thesis can predictably be raised during an election campaign period, when local issues and funding promises are at the fore.

Once on the political stage, a problem will be promoted and debated by a series of actors. The range of actors involved has shifted from traditional models exclusively involving politicians and bureaucrats to a wider set, including the private sector, interest groups and media; and their wider range of values and beliefs are incorporated into the policy process (Walt et al. 2008).

It is important to know who the seen and unseen actors may be, what political or other resources they hold, and what their motivations might be. Roberts et al. (2004) express this well when they write of 'position, power, players and perception': strategies used to shape problem identification. Deals can be made that sway some from their position on an issue; political assets can be exploited to strengthen or undermine groups; players can be



mobilised for or against a particular position; and perceptions can be altered by questioning data, attacking theories and altering associations.

Policy-makers have the discretion to choose the form of policy response, one that may affect the policy's acceptance and outcomes. Policy responses can be classified as distributive, where the policy provides for public services or benefits; regulatory, where certain behaviours are required through mechanisms of restriction or imposition; self-regulatory, favoured by affected organisations as they retain the ability to control their own regulation; and redistributive, where the response aims to change the distribution of services, wealth or rights between public groups to achieve greater equity (Lowi 1964). Each form of policy response will vary in its appropriateness according to the physical and social context of the policy problem, its cost, its reception by the public and key interest groups, and its ease of implementation. For example, a policy may move smoothly through the cycle if it is perceived as distributive, but may face opposition if it is framed as redistributive in nature and people perceive that they and their interests are funding the redistribution.

Howlett argues that the choice of policy instruments—voluntary, regulatory, direct service provision, or even information and disinformation—will depend on a mix of the perceived legitimacy of the government, who will be affected most by the intent of the policy, and how many actors, with what degree of influence, are involved in the process (2000). Howlett outlines how instruments can be used at each stage of the policy process to manipulate outcomes, and goes as far as to say that the fundamental purpose of procedural policy instruments is to manipulate the process (Howlett 2000).

The implementation stage can open up further opportunity for influence on policy outcomes, when 'bottom up' approaches provide considerable discretion on the part of managers on how to implement policies (Sabatier 1986). Discretion opens up interpretation, and interpretation leads to differences in effectiveness, efficiency and outcome (Buse, Mays & Walt 2012).

Even evaluation mechanisms provide much potential for shaping outcomes, real or perceived. While formative evaluation can occur early in the implementation process, and be aimed at providing advice for modifying the implementation, a summative evaluation

mechanism, where a 'verdict' as such is made about the overall ability of the policy to meet its objectives, gives more scope to render a policy a success or failure (Buse, Mays & Walt 2012).

### Downs' Issues Attention Cycle

In contrast to the cyclical and structured nature of the policy cycle, Downs (1972) offers an alternative model that sees policies as entering and exiting the policy arena in stages. The stages submit to the reality of public opinion and public enthusiasm as a key factor in the policy's move forward.

Stage 1 starts with a problem that exists but has yet to capture public attention. Stage 2 results in 'alarmed discovery' and an initial outpouring of public enthusiasm to resolve an issue. Stage 3 indicates the turning point in public enthusiasm as policy measures are implemented to address the issue but their cost begins to depress public sentiment. An understanding of the extent of sacrifice to be borne begins to reach members of the affected community and causes acknowledgement that such sacrifices might not be easily overcome, and might not be acceptable. Stage 4 results from this gradual decline in public willingness to pursue the policy agenda. Stage 5 is the post-problem stage, and can include a range of outcomes. The issue may be neglected and have no substantive outcomes or resolution,, although there may be some measures remaining that to mitigate the problem in some way. There may have been sufficient discussion of the issue that research into improved methods or technologies is under way and the likelihood of a less burdensome solution is not impossible in the future.

Downs (1972) is clear that not all policy issues are captured by this cycle. Only those affecting a minority rather than a majority, or provide a benefit to the majority and suffering to a minority, or that have limited exciting qualities to sustain media and public attention will move through the cycle. Other issues can be more entrenched, affect too many people, or remain ever-changing and ever-looming. Certainly the ongoing and indiscriminate nature of cancer makes it less likely that cancer services will move through Downs' cycle, but particular proposals for service delivery and design may well meet Downs' description.

## Theoretical Frameworks

While a model such as Downs' seeks to describe, theories predict and explain—explain our assumptions in making sense of the world, explain causation, and explain how we know what we know (Maddison & Denniss 2009). Ultimately an analysis of public policies results in many 'why' questions arising, and theories serve to answer these questions in various ways (Cairney 2012).

Which theoretical framework is most applicable to an analysis of public policy relating to radiation therapy services in Tasmania depends on personal assumptions about the policy process and which of its factors are most important. No one theory or framework will be perfectly descriptive of any particular policy topic, and each will have its proponents and its critics.

### Pluralism

Pluralism is a classic group theory that focuses on the role of groups or social networks in determining policy, advocated most notably by Robert Dahl (Maddison & Denniss 2009). Pluralism sees power and resources as distributed widely across the groups participating in the process, with the state as a relatively neutral decision-making body (Addicott & Ferlie 2007). Decisions are reached through negotiation and compromise rather than conflict, with the state then forming policy based on this consensus (Addicott & Ferlie 2007). Frenk and Moon (2013) discuss pluralism as being evident in multi-national organisations such as WHO, UNICEF, and international aid organisations that have developed to respond to global health issues.

This theory offers, on face value, some strong relevance to an analysis of health policy. Health policy is one of the few policy areas that stretches across all demographics and will normally involve many interested stakeholders. Ultimately, policy produced to serve improvements in health care accessible by all will be seen as worthy of robust negotiation and consensus. A repeated and obvious criticism of this model is that it fails to properly consider the power imbalances that often exist between policy actors, or the capacity of some actors to become integral to the decision-making structure (Maddison & Denniss

2009). The assumption that the state is neutral in its decision-making is also criticised for its failure to accept the state as a policy actor with its own values, agenda and power.

## Elitism

Elitism is somewhat the antithesis of pluralism in that power is not seen as widely dispersed but rather concentrated among those who have higher education, income and status (Graduate Center for Public Policy and Administration 2002). These elite are the dominant policy decision-makers, and policy flows from them to the masses, including public officials and administrators, who simply carry out their decisions (Graduate Center for Public Policy and Administration 2002).

Maluleke (2010) takes this further, describing the elite as kingmakers, able to influence not only policy formation but who is elected to public office and who sits in positions of authority or decision-making. Public officials are 'kings', the visible arm of policy-making. Community members are 'actives', 'interested citizens' or 'apathetic citizens' according to their level of interest and involvement, but their capacity to affect decision-making is limited.

This theory may apply well to health policy in explaining the power and resources of the medical profession, the pharmaceutical industry and associated bodies. For example, in 2010 health care lobbyists in the USA spent \$521 million influencing public officials and federal agencies, making it the second largest lobby group in the USA (Buse, Mays & Walt 2012). Palmer and Short (2014) believe the medical profession holds an unrivalled position of power in influencing health service design and policy, as well as in determining numbers of specialist training places. This comes as a consequence of its male-dominated ranks and its prestige, drawn from the historically high socioeconomic background of medical professionals (powerful men making the profession powerful as a consequence). This is despite the fact that medical professions make up only 17% of registered health care professionals, while nurses, who make up the majority of the health workforce at 63%, have considerably less influence (Australian Institute of Health and Welfare 2012a).

This theory is not without its faults, however. The most substantive criticisms of this view are its inability to consider fully the power of the masses when their values and expectations

conflict with the elite, and the tendency for this theory to view the masses as 'ill-informed' (Maluleke 2010). It does not account sufficiently for policy wins by minority groups or the general public in the face of a dominant opposition.

### Punctuated Equilibrium Theory

Baumgartner and Jones developed punctuated equilibrium theory to respond to focusing events that can draw issues into the policy spotlight, such as natural disasters, unprecedented events or media stories (O'Neal 2011). Policy change occurs over a series of incremental steps, punctuated by moments of major change. Focusing events can lead to significant and drastic change in an otherwise static policy environment. Gun reform in Australia in the late 1990s and national security reforms in the aftermath of the 9/11 attacks are both examples of such events.

Punctuated equilibrium theory asserts that natural disaster and other focusing events can have a destabilising effect on society; an immediate policy response is often required to recreate the sense of stability (O'Neal 2011). Such a policy response fits well with Howlett's concept of windows of opportunity (1998). While Howlett concludes that most issues can find their window of opportunity in routine and predictable cycles, he acknowledges that significant, unpredictable events can also create a window.

Punctuated equilibrium theory is developed further by Cairney (2007), who states that it is about problem definition and policy-makers lacking resources and time, leading to an overcrowding of the policy stage. Only issues that pierce the public conscience sufficiently will move onto the political agenda. Cairney links this to health policy debates using the example of the tobacco industry. If problem definition can lead to more prominence on the policy stage then problem definition will become the focus of competing coalitions. The resources of the tobacco industry were such that it was able to frame problem definition and control policy debate through much of the twentieth century until sufficient new technical health information forced a change to the policy position (Cairney 2007).

The same may be said of health services in Tasmania. While unions and professional groups have a mainly consistent view of risk management and sustainability in the delivery of health services, and support service centralisation and rationalisation, regional communities have

are largely consistent in wanting to retain existing services and in being concerned that changes might negatively affect them (Shannon 2010).

## Coalition Structuring

Lemieux's theory of coalition structuring, like the ACF discussed further in this chapter, sees policy as debated by series of coalitions (Breton et al. 2008). This theory states that coalitions form only in response to looming policy threats or opportunities, rather than having the entrenched core beliefs and long-term policy interaction characterising Sabatier's advocacy coalitions, and reflect the current policy environment rather than shared beliefs. Lemieux argues that members will constantly review their involvement in coalitions in terms of the costs of association, the level of risk, the strength of their affinity and collaboration, and their control over decision-making. This concept links strongly with the work of Cairney (2007), who comments on the temporary nature of some coalitions in regard to the tobacco industry and anti-tobacco coalitions in the United Kingdom. Cairney notes that he struggled to explain temporary alliances based on self-interest, such as that demonstrated by the British Beer and Pub Association when a proposal to ban smoking pubs but exempt private clubs threatened economic self-interest: the association joined the anti-tobacco coalition for a comprehensive ban (Cairney 2007).

A theory like Lemieux's can account for changes to coalitions and their membership. Some might arise solely during the course of a particular policy debate, and thus may fit Lemieux's model. Such transient coalitions, which only enter a policy debate when they have information necessary to motivate them, are described as latent actors by Sabatier (1988). A regional community during a proposed change, or a community during an election period where political promises are used to woo voters, are key examples of such latent coalitions. While they are concerned about service delivery in their communities, they often do not become involved in policy decision-making until a specific potential loss is identified (Shannon 2009). It is the art form of a political candidate or party to identify latent actors and to use information to mobilise them during such peak times as elections (Sabatier 1988).

## Policy Narratives

Policy work is the construction of social problem, and understanding the ways in which language is used in policy-making is helpful in that it reminds us that how we name and label particular issues and identities is a deeply political act (Bessant et al. 2006). Shanahan et al. (2011) see narrative as a missing element of theories such as the ACF, and write with a symbiotic approach to the ACF and Narrative Policy Framework (NPF). Public policy is seen, in part, as socially constructed, and actors ascribe certain meaning to it, influenced by the words and symbols used by stakeholders. These narratives are strategically constructed to maximise their power to influence actors in favour of a policy position, and the general public more easily engages with them than with, say, scientific discourse.

Policy narratives are discussed in terms of having plot, characters, setting and a preferred outcome (Shanahan, Jones & McBeth 2011). Depending on the position of the narrator, characters can be portrayed as heroes or villains, and perspectives can be constructed according to whether the narrators see themselves as winners or losers. Emotive language like 'rorts' or 'death cults' is deliberately used to induce a strong reaction in listeners. This use of language to portray one's opposition and oneself aligns closely with Sabatier's discussion of 'the devil shift', whereby actors will impugn the motives and behaviour of their policy rivals while portraying themselves as reasonable and attuned to the public's needs (Sabatier, Hunter & McLaughlin 1987).

The NPF identifies policy change as occurring when a new story becomes dominant and creates a new normative setting or value prioritisation, without any substantive change to the facts (Shanahan, Jones & McBeth 2011). This holds some merit when considering health services in Tasmania. Consistent efforts to change the matrix of service design and delivery (Shannon 2005, 2009, 2010) presented the same issues of sustainability and patient risk in the current structure; yet the narrative told by opponents, as well as a strongly regionalised media, resonated more strongly, creating fears of how altered services in their local area might negatively affect hearers. The narrative about loss of services dominated the policy debate, not the technical information presented by the proponents.

## Bounded Rationality

Rather than seeking to explain the policy debate and power dynamics within policy-making, the concept of bounded rationality has been used over successive decades, by several major policy-making theorists. Individuals are considered to be 'boundedly rational' in that they wish to achieve a particular policy outcome but may be unsure of how to achieve this or how to process all the information relevant to an issue (Jenkins-Smith, Nohrstedt, et al. 2014). Originally proposed by Simon (1947), the concept of bounded rationality essentially 'involves the decision-maker choosing an alternative intended not to maximise his values but to be satisfactory or good enough and enables the administrator faced with a decision to simplify by not examining all possible alternatives' (Ham & Hill 1993, 84).

The concept of bounded rationality describes how information is sourced and prioritised in order to allow policy decisions to be made. It rests on several principles (Jones 2002):

- people intend to be rational but cognitive and emotional constitutions may make them act in non-rational ways
- emotion is a major mechanism used to weigh the relevance of information
- people can become emotionally attached to prepared solutions encoded in their memories, which makes it difficult for them to change their minds
- limited attention spans can lead people to choose whichever option exceeds the aspirational level they have attached to an issue

This may serve as a complementary theory to account for decision-making by actors or coalitions in health policy, especially when there is a seemingly contradictory position between the evidence being provided by technical experts and the decisions being made by policy-makers. In the case study of radiation therapy services in North West Tasmania, the technical experts, namely the doctors, held a privileged position and demonstrated some power over health care reforms. However, changes to the delivery of radiation therapy services there appear to have been made contrary to their views, and bounded rationality may explain this.



## Localism

Another concept that may add to policy analysis theory is localism. Localism can result from a sense of shared identity and lead to members of a community becoming involved in decision-making on issues of local significance, or at least to wishing to become involved (Dare 2013). Engagement of the local community in decision-making can achieve or add to a balance between a government's and a community's needs or expectations. However, the state government is 'perceived to be failing to achieve this balance, criticised for the on-going use of traditional command-and-control strategies that fail to adequately hear, and respond to, the diversity of concerns and conditions facing communities' (Dare 2013, 592).

The community desire, or at least the perceived community desire, for a local radiation therapy service may be seen as stemming from a sense of localism. With a long history of health service reforms affecting the North West and examples of local community opposition to such changes (as discussed previously in this chapter), localism may be a sentiment that is evident in the case of radiation therapy services in the region, and may be a motivating force behind boundedly rational decision-making or evidenced in some other way. It may be seen in the beliefs and actions demonstrated by coalitions rather than as a stand-alone explanatory theory.

## Advocacy Coalition Framework

Sabatier's advocacy coalition framework (ACF) was developed to deal with 'wicked' problems, 'those involving substantial goal conflicts, important technical disputes, and multiple actors from several levels of government' (Sabatier & Weible 2007, 189).

Frameworks are described as a means of identifying elements and relationships for policy analysis, offering diagnostic and prescriptive inquiry and a list of universal elements that theories focusing on the same phenomena would need to include (Ostrom 2007); as Schlager puts it, 'Frameworks organize inquiry, but they cannot in and of themselves provide explanations for, or predictions of, behavior and outcomes. Explanation and prediction lie in the realm of theories and models' (2007, 293).

The ACF bridges a gap between a framework and a theory in that it provides a universal structure that is applied in policy analysis but also seeks to explain belief change and policy

change, giving it the explanatory and predictive elements of a theory (Sabatier & Weible 2007).

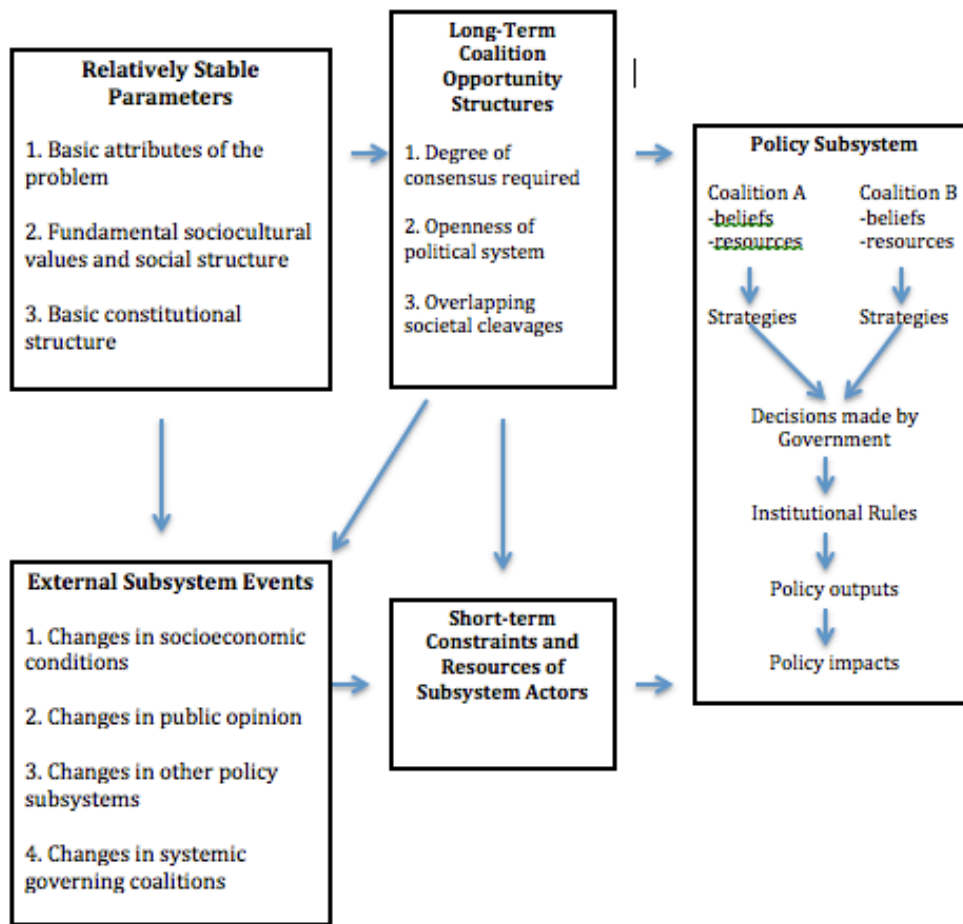
Initially introduced by Sabatier in his seminal work *Top-down and bottom-up approaches to implementation research: a critical analysis and suggested synthesis* (1986), the concept was developed in multiple articles and later in *Policy Change and Learning* (1993) and *Theories of the Policy Process* (2007 1<sup>st</sup> edn and 2014 2<sup>nd</sup> edn). The framework was developed in response to what Sabatier and Jenkins-Smith saw as three shortcomings in policy analysis: inadequate discussion of causality in the policy process; limitations of current implementation theories; and the need to include scientific and technical information more fully into policy theory (Weible, Sabatier & McQueen 2009).

The ACF is described as a framework that can potentially deal with entrenched policy issues that might produce conflicting goals, technical disputes and multiple actors (Sabatier & Weible 2007). The important difference between Sabatier's concept of advocacy coalitions and theories such as elitism and public choice theory is that coalitions are defined by their beliefs rather than by their exercise of self-interested power (Sabatier & Weible 2007). That is not to say that power is not identified as a factor of influence, but rather that it is wielded in order to promote an ideological position and not an economic self-interest, which sets the ACF apart from both pluralism and elitism. It does not exclude the possibility of altruistic behaviour, and given that health issues such as cancer are seen as an issue for all society to overcome, altruism appears to have its place (Sabatier 2007).

Policy actors group themselves into advocacy coalitions according to beliefs. These coalitions join the policy debate against other coalitions, interacting over long periods, usually a decade or more, and compete for influence over policy by proposing solutions to policy problems (Sabatier & Weible 2007). This seems to sit well with the concept of health policy analysis as it tends to deal with entrenched issues that require proactive measures and involve the same types of coalition: of health professionals, patient representatives, industries, political parties, and, during periods of specific policy proposal and reform, local communities. Each is bound by a common set of beliefs and values and can include a broad range of actors, from politicians and bureaucrats to community groups, researchers and professional bodies.

The beliefs underpinning coalitions may be divided into levels according to their degree of changeability. Deep core beliefs are the deep-rooted values and beliefs about how the world should be across all policy subsystems. The NPF calls these the 'glue' that holds a coalition together and protects it from internal and external conflict (Shanahan, Jones & McBeth 2011), a term also used to describe shared core beliefs in the ACF (Sabatier & Jenkins-Smith 1999). There are also policy core beliefs, beliefs and commitments specific to the policy and subsystem in question; and secondary aspects, which are narrower beliefs relating to causal factors and the seriousness of the policy problem (Jenkins-Smith & Sabatier 1994). Jenkins-Smith and Sabatier believe these deep core beliefs are central to the structure of a coalition and are not easily changed, whereas policy core beliefs may change over time through the process of learning (1994). Core beliefs and their impact on the structure of the coalition create perceptual filters which can alter the way in which the same information may be processed and set views reinforced, such as the right to universal health care or the need to keep major services centralised (Sabatier & Weible 2007). Such entrenched perceptions do well to explain why there is always ongoing policy conflict.

Policy debate takes place amidst policy subsystems, which are separate from but invariably influenced by the broader political environment. Subsystems and participant behaviour are affected by two exogenous factors: relatively stable parameters, and external events (Sabatier & Weible 2007). Relatively stable parameters include resources, societal values, the basic attributes of the policy problem, and legal and constitutional structures. These tend to remain, by their nature, stable and resistant to change. External events include changes to socioeconomic conditions, a change in ruling party, and external shocks and impacts from other subsystems. Like Baumgartner's focusing events or Howlett's window of opportunity, the dynamic external factors, such as changes to political regime and socioeconomic conditions or natural disasters, can quickly start a cascade effect of major policy reform. This is in contrast to Lindblom's incrementalism, which acknowledges policy as being made in small steps and not as reacting to external events (Cairney 2012). The subsystem and its impacts are represented as a flowchart (see Figure 3) below:



**Figure 4 Advocacy coalition framework flowchart (Weible et al. 2011)**

Policy change is identified as triggered in four ways: changes or shocks to the external environment; policy-oriented learning; more recently, internal shocks and their reflection on the failure of current practices of a coalition; and, also recently, alternate dispute resolution, brought about by stalemates, member commitment and leadership (Weible, Sabatier & McQueen 2009). Policy-oriented learning occurs when new experiences and new information relevant to the attainment of policy objectives lead to enduring alterations in behaviour and intent (Sabatier & Weible 2007). Sabatier (1988) sees learning as a natural part of the policy process, with coalitions fundamentally committed to better understanding the world in order to improve their policy positions. It can come about from new technical information and understandings of best practice, but these will achieve change only in secondary beliefs, not deep core beliefs. It can also result from changes to the external environment, such as a change in government, which can in turn alter policy beliefs but only if the opportunities presented by external events are harnessed by the coalition advocating

change (Jenkins-Smith & Sabatier 1994). Policy learning itself is divided into three levels: micro-learning, which focuses on the 'puzzling' of policy issues by individual actors involved in the policy process in order to gain further certainty; meso-learning, where an increase in knowledge and understanding about the policy issue can be achieved at an organisational level and allow that organisation to better advocate for its policy position; and finally macro-level learning, which involves policy decisions made in one or even more institutional systems that can be similar in nature (Moyson, Scholten & Weible 2017). Research has suggested however that policy learning is not necessarily conducive to policy change. This can be due to the presence of other factors that impact on change, such as the level of coercion to adopt a certain policy response, the involvement of convincing policy entrepreneurs, or changes in governing coalitions (Dolowitz & Marsh 2000) (all of which are discussed in this study as explanations of policy change). Policy learning can also be overridden by the exercise of power and personal ideologies (Moyson 2014), which can result in policy change that runs contrary to the learning derived from new information or changed beliefs. This means that understanding the mechanisms for policy change can often be very different to understanding the instances of policy learning.

The ACF hypothesises that the policy core of any program will not change as long as the coalition that brought it into being remains dominant (Jenkins-Smith & Sabatier 1994). It is here that we see the importance of policy core beliefs, which are the fundamental source of conflict and division between coalitions.

While deep core beliefs are largely immutable, they are also broad. Policy beliefs are more immediately relevant to the policy subsystem actors and therefore losses and gains in this area will be of more salience to the concerns of the coalitions involved (Zafonte & Sabatier 1998).

The ACF has, like several other theories, incorporated the idea of bounded rationality in decision-making. Policy actors are not considered to be perfectly rational decision-makers who 'tend to privilege what they believe rather than accept information that might challenge those beliefs' (Moyson et al. 2017, 165). This bounded rationality acts as a cognitive filter that influences selective processing, serving to reaffirm core beliefs and reject information that contradicts them (Jenkins-Smith, Silva, et al. 2014). Information is often

rejected by use of the 'devil-shift', whereby actors will "impugn the motives and/or reasonableness of their opponents" and see their actions in a manner more harshly than others in the policy community might (Sabatier, Hunter & McLaughlin 1987, 451).

The role of bounded rationality in regard to the establishment of a local radiation therapy service in NW Tasmania was examined in an article (West et al. 2017). In this article, the authors highlighted that the policy debate was one of conflicting priorities, with the community expressing a perceived desire for a local service while health professionals and political representatives worked towards a more centralized service model for health. The authors found that the health and policy coalition that arose during this policy debate was akin to the scientific community that is part of the concept of bounded rationality. This coalition held the specialized scientific knowledge in regards to this policy area. However, the intervention by the Federal Government on this issue in 2010 moved the power dynamics so the true policymaking power rested with the most hierarchically superior tier of government, being the Federal Government. Bounded rationality was demonstrated by political parties and candidates vying for power in the 2010 Federal Election, who sought to gather only the amount of information sufficient to for the basis of a decision that would win popular support. In keeping with the theory of bounded rationality, the idea of a local service was a pre-packaged solution that was easily adopted by the policymakers. Although scientific information was presented by the opposing side of the policy debate in regard to the sustainability of such a service, this position could not 'find traction'. The paper demonstrated the importance of scientists and other 'experts' in the field of health understanding the role bounded rationality can play in the policymaking process and the need to accept that scientific information may not always have the effect of triggering policy learning. Once acknowledged, those involved in health policy can focus instead on framing a more effective message or gaining the best outcome for their policy positions amidst this reality.

Changes made by Sabatier to the ACF to incorporate further extension to the concept of policy learning are highlighted by Schlager (2007). Policy change is now also acknowledged as occurring as a result of internal shocks, like focusing events or negotiated agreements that result from a 'hurting stalemate'. Such stalemates occur when the status quo is deemed

unacceptable and not achieving the intended policy outcomes; coalitions at such times become more accepting of change.

Policy learning between coalitions is much less common as it involves one coalition developing an argument so persuasive that the view of the other coalition must change in response. The perceptual filters used by each coalition to reinforce core beliefs tend to filter out information that is at odds with those beliefs, making change that much harder when initiated externally (Sabatier & Weible 2007). It is therefore likely to occur only in situations of low conflict and high collaboration, and not in intractable policy debates (Shanahan, Jones & McBeth 2011). Sabatier takes this concept further and discusses the concept of the 'devil shift' whereby by one coalition will over-emphasise the negative underpinnings of their opposing coalition's behaviour, motives and actions (Sabatier, Hunter & McLaughlin 1987). Ultimately the extent of the 'devil shift' and the likelihood of and mechanisms for attempting policy learning all depend on the nature of the subsystems and the level of conflict within them (Weible, Sabatier & McQueen 2009).

Between each coalition Sabatier also includes policy brokers, a third group whose role is to broker compromise between the different positions (Sabatier 1988). Such brokers may be elected officials, high-level civil servants or advisory committees, but the government of the day cannot always be considered a policy broker. The ACF acknowledges that brokers often have a political position and can move across the continuum between broker and coalition member (Jenkins-Smith & Sabatier 1994; Sabatier 1988). Weible & Ingold (2018) go further and state that policy brokers are actors who are constant within the subsystem but not within a coalition, and that these brokers specifically want to minimize conflict, rather than simply seeing it as their role of promote compromise.

Formal authority to make policy decisions is considered to be one of the resources held and used by coalitions to achieve their policy aims, which in itself indicates that policy-makers (governments) are an active coalition in some policy debates (Weible et al. 2011). If, as Shannon (2009) states, policy brokers are more concerned with creating stability than achieving particular political goals, this seems incongruent with the acts of governments. Governments, and the political parties that underpin them, create and sustain political credibility on policy achievements and initiatives. They can therefore be inextricably tied to

the policy debates that ensue. As Sabatier states, ‘people get involved in politics at least in part to translate their beliefs into public policy’ (1988, 132).

A recent modification to the ACF reveals that political systems where no one political party has a clear path through both houses of parliament, such as that in the Australian Commonwealth and the state of Tasmania, are increasingly common and result in a more decentralised decision-making structure (Sabatier & Weible 2007). The more parties that are involved in decision-making, the more coalitions can be deemed to be active in that particular policy community. The higher the degree of consensus required, such as garnering support from minor parties or independents, the greater the need for coalitions to be inclusive of wider views and policy objectives or to negotiate with others. Such inclusion and negotiation will minimise the chances of appeal and dissatisfaction in the future and ultimately promote trust, mutual acceptance and compromise (Sabatier & Weible 2007).

Modification of the ACF has largely been achieved through the testing and subsequent alteration, addition and clarification of the hypotheses that underpin the framework. The framework has been developed to its current state by regular analysis of research that has applied it, and the degree to which research supports or disproves existing hypotheses. The latest revision of the framework incorporates twelve hypotheses in three areas (Table 7).

**Table 7 Advocacy coalition framework hypotheses (Jenkins-Smith, Nohrstedt, et al. 2014, 195, 199-200, 203-204)**

Coalition Hypotheses
<ol style="list-style-type: none"> <li>1. On major controversies within a policy subsystem when policy core beliefs are in dispute, the line-up of allies and opponents tends to be rather stable over periods of a decade or so.</li> <li>2. Actors within an advocacy coalition will show substantial consensus on issues pertaining to the policy core, although less on secondary aspects.</li> <li>3. An actor (or coalition) will give up secondary aspects of her (its) belief system before acknowledging weaknesses in the policy core.</li> <li>4. Within a coalition, administrative agencies will usually advocate more moderate positions than their interest-group allies.</li> <li>5. Actors within purposive groups are more constrained in their expression of beliefs and policy positions than actors from material groups.</li> </ol>
Learning Hypotheses



6. Policy-oriented learning across belief systems is most likely when there is an intermediate level of informed conflict between the two coalitions. This requires that (1) each have the technical resources to engage in debate, and (2) the conflict be between secondary aspects of one belief system and core elements of the other or, alternatively, between important secondary aspects of the two belief systems.
7. Policy-oriented learning across belief systems is most likely when there exists a forum that is (1) prestigious enough to force professionals from different coalitions to participate, and (2) dominated by professional norms.
8. Problems for which accepted quantitative data and theory exist are more conducive to policy-oriented learning across belief systems than those in which data and theory are generally qualitative, quite subjective, or altogether lacking.
9. Problems involving natural systems are more conducive to policy-oriented learning across belief systems than those involving purely social or political systems because, in the former, many of the critical variables are not themselves active strategists and because controlled experimentation is more feasible.
10. Even when the accumulation of technical information does not change the views of the opposing coalition, it can have important impacts on policy—at least in the short run—by altering the views of policy brokers.

#### Policy Change Hypotheses

11. Significant perturbations external to the subsystem, a significant perturbation internal to the subsystem, policy-oriented learning, negotiated agreement, or some combination thereof, are necessary, but not sufficient, sources of change in the policy core attributes of a governmental program.
12. The policy core attributes of a government program in a specific jurisdiction will not be significantly revised as long as the subsystem advocacy coalition that instated the program remains in power within that jurisdiction—except when the change is imposed by a hierarchically superior jurisdiction.

These hypotheses suggest some ready areas for testing and some guidance as to how coalitions may be identified and analysed. The continuity of policy core beliefs and secondary beliefs, the presence and stance of administrative arms of coalitions, the level of learning and conflict, the impact of technical information, and the impetus behind policy change can all be considered in the context of radiation therapy services in North West Tasmania.

It is for the reasons above – the recognition of individuals and beliefs (such as the desire for local delivery of radiation therapy services) at the core of policy debate, and the capacity for learning (such as that of the Tasmanian government by the health community on the need

for service rationalisation for safety and quality reasons) and impact from external sources (such as the federal takeover of the Mersey Community Hospital) – that the ACF appears to be the most applicable theory to the analysis of the delivery of radiation therapy services through public policy in Tasmania. Health issues cut across all social strata, requiring motivation to serve the common good, but exist within an inherently political environment, with actors from the health professions, community groups and political structures all promoting varying policy positions based on their beliefs of the best way forward.

### Application of the ACF in health policy

Originally designed to evaluate land use policy, the ACF has evolved and been widely adapted across multiple policy areas. This includes growing, substantial application to the sphere of health policy. Between 2007 and 2014 public health was the second most common policy area to which the ACF was applied, after environment and energy (Pierce et al. 2017). Aspects of health that have seen the largest use of the ACF in research and analysis include tobacco regulation, reproductive issues, screening and prevention services, and lobbying for funding for younger generations in regard to the social determinants of health.

The evolving policy response to the tobacco industry has been examined across multiple countries, including the United Kingdom, Japan and Canada (Breton et al. 2008; Cairney 2007; Farquharson 2003). Cairney (2007) examines the decades-long period of stability in the tobacco industry, followed by what appeared to be a quick succession of policy changes and ensuing regulation, debating whether industry regulation was the result of sudden change, brought about by emerging scientific evidence on the harms of smoking, or a series of incremental changes that made far-reaching regulation inevitable. Gibson (2004) adds uncertainty to the notion that sudden change was brought about by new scientific evidence, noting that such evidence had been around for decades prior to substantive change being adopted.

Cairney (2007) divides the debate on tobacco regulation into two predictable coalitions: the pro-tobacco regulation coalition, which was largely of public health advocates, and the tobacco industry. He argues that change took a long time to come about, despite emerging evidence on the harms of smoking, largely because of the resources and adaptability of the

industry. The poorly-funded, emerging, pro-regulation coalition was unable to shape the image of tobacco use for a long time, battling the resources and capacity of the tobacco industry, a finding reiterated by Farquharson (2003). The industry ingratiated itself to its critics by adapting to calls for change, such as introducing filters on cigarettes, funding medical research and adopting some voluntary advertising restrictions.

The industry was also able to use its resources to constantly scrutinise and reframe scientific evidence on the level of harm from smoking, creating scepticism. Breton et al. (2008) develops this argument further, noting that the industry was able to create concern that regulation would negatively impact on its capacity to continue funding of arts and sporting events, and would damage trade and the economy. Breton et al. (2008) see the strategy to focus on the economy as an acceptance over time that scientific evidence on the harms of smoking is a stable parameter; the industry therefore chose to attack regulation from the angle of economics rather than of public health.

Such capacity to control and frame the debate is linked to the ACF hypothesis that there is unlikely to be a large impetus for change when a dominant coalition (like the tobacco industry) is unwilling to change the status quo (Nagel 2006). This view is echoed by Gibson (2004) and Shannon (2010), who state that a dominant coalition can rely on its resources to shape policy in a way most suited to its policy beliefs, even in the face of research that indicates otherwise. Cairney (2007) sees such a capacity as an indication that influence over policy brokers, and subsequently influence over decision-makers, can be more effective than any other coalition strategy, and provides insight into the notion of self-interest among members of coalitions; he instances the role of the British Beer and Pub Association, a long-term member of the anti-regulation coalition. The Association, when faced with the likelihood of smoking being banned in pubs but allowed in private clubs, switched sides and began advocating for a sector-wide ban (Cairney 2007), an action that is more in keeping with Lemieux's theory of coalition structuring, where members are constantly reviewing their involvement in coalitions based on costs and benefits. This creates questions about the long-term stability of coalitions under the ACF when the self-interest of one member is undermined by the shared policy beliefs.

Breton et al. (2008), in their study of tobacco regulation in Canada, made a notable finding in regard to the need for government officials to seem detached from policy debate and coalitions. In this case, government officials involved in public health created and funded an NGO with the specific intent of lobbying for tobacco regulation, so that they could continue to maintain their impartial roles without raising public concern about government interference in public debates.

In their conclusion, Breton et al. (2008) highlight their perceived limitations of the ACF. While they see its application as useful in studying changes to tobacco regulation, they believe the ACF is limited in its application to such complex health issues as health inequalities, obesity or physical inactivity. They see these kinds of issue as attracting a more complex array of actors across various sectors and levels of government, thereby making them more difficult to sort into clearly defined coalitions.

In an article by Princen (2007) about the internationalisation of policy and lobbying, the author illustrates how coalitions like the tobacco industry can bypass certain levels of government or layers of policy decision-making and strategically lobby the level that best serves their cause. A prime example of this in health policy is the takeover of the Mersey Community Hospital in Latrobe by the federal government (Shannon 2010). Lobbying by the concerned local community and health care staff was aimed at the federal level, not just at the state where responsibility for health funding fell. This was strategically timed to coincide with a federal election, thus creating an impetus for Commonwealth support.

The application of the ACF to Tasmanian health policy, in particular, is developed in several articles by Shannon (2005, 2009, 2010). In *Sailing through the 'perfect storm': health policy and planning in Tasmania* (2010), Shannon discusses the evidence of policy learning across and within coalitions. The development of the Tasmanian Health Plan in 2007 is seen as a result of the policy community (comprising the government, health professionals and health unions) learning of the need for change based on best practice elsewhere. The need for change and the rationale for it were developed into a communications strategy aimed at the Tasmanian public. Messages focusing the need to rationalise services at regional hospitals in Ouse, Rosebery and the Mersey were meant to garner public support, but the result was that an increase in understanding by the community of what was intended led to heightened

concern and objection. Nagel (2006) comes to a similar conclusion on the capacity for education campaigns to heighten perceptions of threat to personal interest, in his study of a proposal to change the model of care in regard to worker's rehabilitation. The educational campaign in this case resulted in the formation of a new opposing coalition and an active attempt by them to halt the proposed change; the aim of using technical information to create learning between coalitions only resulted in change within coalitions. Community concern and the takeover of the Mersey Community Hospital were 'external shocks' to the policy subsystem and resulted in considerable delay to reform (Shannon 2010). Partial reform was only brought about by negotiated agreements and the inclusion of stakeholders from outside the subsystem, such as local employers and utility providers, and may be indicative of a hurting stalemate.

In an earlier article, Shannon explores the unique context of Tasmania's political system and the impact this has had on power within the health subsystem (2009). While the long-standing privileged position of the medical profession in shaping health policy is noted as a systemic factor within this policy subsystem, community-level concerns have held a similarly strong influence. Aspiring candidates compete, even with their party colleagues, for votes under the Hare Clark system in a highly regionalised state, leading to what Shannon sees as a higher degree of responsiveness by candidates and parliamentarians to the wishes of the local community. This has reinforced reluctance on the part of many politicians to enact change that would draw services away from the community they represent. While consumers might not have their views strongly represented by a coalition of well funded and well networked organisations, and while individuals may not be active participants in the policy-making process, their views are still clearly heard and represented via political representatives and the media. This opens an interesting question about the power of non-active participants (Sabatier's latent actors) not normally associated with a coalition, and their impact on policy-making.

Reproductive issues, including abortion, contraception, embryonic stem cell research and assisted reproductive technology, have also been discussed in terms of the ACF in recent years. One analysis of a bill to mandate the offer of emergency contraception to sexual assault victims in Tennessee (Schorn 2005) attempts to demonstrate that Sabatier and Jenkins-Smith are incorrect when they state that 'problems for which accepted quantitative

data and theory exist are more conducive to policy-oriented learning across belief systems than those in which data and theory are generally qualitative, quite subjective, or altogether lacking' (1999, 124). The same demonstration is made by Gibson (2004) in regard to cancer screening.

Schorn discusses contraception as a highly emotive policy issue that results in quantitative technical data yielding little or no policy-oriented learning. Although legislators may understand how emergency contraception works, fear of societal perceptions of contraception, and the successful linking of the issue to the abortion debate by its opponents, have stymied change. Her analysis concludes that scientific evidence is not sufficient for change and that scientists must be involved in its interpretation and advocacy; and she disagrees with Sabatier and Jenkins-Smith's hypothesis that even if such evidence does not impact on learning within oppositions, it will impact on learning by policy brokers and governments (1993a). This has parallels to the lack of learning by opposing coalitions during the health reforms proposed in Tasmania, although governments and brokers became more committed to the need for policy change as a consequence (Shannon 2010). The fear of a loss of services by the local community overrode any learning in the face of expert technical information about the lack of sustainability of such services. Indeed, the same expert advice on the lack of sustainability of a radiotherapy service in Tasmania (Australian Medical Association Tasmania 2010c) resulted in little policy learning by proponents of the service, who ultimately achieved their policy objectives.

The notion of coalitions linking one policy issue to another in order to give weight or opposition to it is developed further Gathje (2009). He notes how a pro-embryonic stem cell research coalition in the USA employed the deliberate strategy of 'keeping pro-choice groups quiet' to avoid linking the abortion debate with embryonic stem cell research. This was because the abortion debate favoured the opposing Christian Right coalition and confused the messaging of the pro-embryonic stem cell research coalition. Messaging was also seen as a crucial tactic for the Christian Right, who notably toned down their rhetoric over time to appear moderate and pragmatic. Gathje illustrates how policy learning, in particular by policy decision-makers, is achieved in a highly subjective and qualitative area. While the pro-embryonic stem cell research coalition tried to keep their tactics focused on the science of the potential of embryonic stem cell research, the stories of disabled or ill

patients, particularly children, swayed some legislators from opposing to embryonic stem cell research to supporting it. This change in legislation was also facilitated by clear changes in the external environment, notably the change in majority from a largely anti-embryonic stem cell research Republican Congress to a more pro-embryonic stem cell research Democratic Congress.

The role of funding in legitimising a policy position is also illustrated. Gathje states that 'modern governments go beyond the traditional duties of regulating certain behaviours and enforcing laws by financing certain activities. When governments choose to appropriate federal funding they are in effect offering their support and approval' (2009, 77). At the time of his thesis, the federal government had neither prohibited such embryonic stem cell research by regulation or legislation, nor has it condoned it by providing federal funding. When considering government funding initiatives like the commitment to build the North West Regional Cancer Centre in Burnie, it is clear how the commitment of funds can be seen as legitimating the need for such a centre in the North West of Tasmania and therefore legitimating the coalition that advocated it.

When studying parental views on vaccination, Wilson et al. (2008) use the ACF to determine what scientific or technical information was used by each coalition and the strength of their respective core policy beliefs. Coalitions were divided between parents who had vaccinated their children without expressing concern, parents who had vaccinated their children but struggled with the decision, and parents who had not vaccinated their children. The study highlights how each coalition gave different priority and trust to technical information, with anti-vaccination supporters turning to alternative medical providers for advice and information rather than traditional GPs. This raises the notion of how scientific and technical information can be sought from sources that reaffirm an already-established belief using perceptual filters.

Wilson et al. (2008) also consider how policies and strategies need to be based on a clear understanding of the beliefs and values of each coalition. They found that the pro-vaccination coalition actually demonstrated the weakest beliefs about vaccination, while the anti-vaccination coalition had the strongest deep core beliefs. This understanding could lead pro-vaccination campaigners to attempt to change the policy beliefs or secondary beliefs of

the anti-vaccination coalition, rather than expending resources confronting their largely immovable deep core beliefs. Similarly, the study found that all coalitions valued a parent's right to choose; any pro-vaccination campaigns should therefore aim to avoid mandatory vaccination policies, which would encounter objections from both sides of the policy debate.

A study of younger generations in Canada and their recognition of the social determinants of health through government funding was undertaken to determine the role of coalition-building in achieving policy outcomes (Kershaw, Swanson & Stucchi 2017). In this article the authors discuss how younger Canadians had not effectively organised themselves into any formal lobby group when it came to the impact of the social determinants of health; which meant there was no coalition competing for government funding to balance the lobbying undertaken on behalf of older Canadians. This void created imbalance, offering few incentives for the government to prioritise investment in early life course stages by comparison with later stages. The result was a larger gap between government budget priorities for younger Canadians than for older cohorts (Kershaw, Swanson & Stucchi 2017, 199).

This outlines the importance of an organised and effective coalition if policy change is to be achieved. Kershaw et al. tested this theory by creating an artificial coalition that gathered momentum over time, with the use of strategically released research papers during election campaigns. The result was the adoption of funding commitments for younger generations in regard to social determinants of health. This article raises the question of whether coalitions need to form organically or whether a policy entrepreneur can create a coalition to suit the policy beliefs of an individual.

This array of research into various aspects of health policy indicates that the ACF has been accepted as relevant and applicable to the health sector. Issues concerning the power of resources on policy outcomes, the use of scientific evidence, creating or switching coalitions, the different levels of government and different spheres of influence and transfer, educational campaign strategies, and problem definition and linking are all explored using the ACF. Such research illustrates that health policy is a complex blend of quantitative scientific data and subjective, qualitative beliefs and interpretations, and indicates that the



ACF may be applicable to the study of radiation therapy services policy in North West Tasmania.

## Summary

This review has provided background information on the search strategy used to locate and disseminate literature; the recent history of cancer services in Tasmania, and recent and current efforts to reform health services; how residents of the North West region of Tasmania, which is classified as regional and remote, are disadvantaged in terms of health outcomes by their geographic location and how this can have implications for mortality, treatment choices and emotional resilience; how Tasmania, and especially the North West, have a unique political structure that serves to promote local issues, like the delivery of radiotherapy services on the North West coast, over traditional party politics; and how the ACF may be used to examine the effect public policy has had on the provision of radiation therapy services to residents of the North West of Tasmania by dividing the debate into coalitions: those in favour of centralised services and those in favour of extended services within the local community.

The ACF has been discussed in detail to explore its origins, its hypotheses, its components that are used for policy analysis, and its application in the sphere of health policy over recent decades. Applying the ACF to this particular policy change enables a more rigorous process for evaluation, as a prescribed model can be used and known hypotheses can be tested. By using the language of the ACF the data collected can be more readily categorized and compared. This language includes ascribing beliefs to actors rather than their statements and actions and grouping actors with shared policy beliefs into coalitions rather than interest groups. This coding by beliefs simplifies the process of policy analysis, allows for greater consistency and structures the 'ideological dimensions' (Weible & Ingold 2018). Also, by defining the relatively stable parameters of the subsystem and its long-term and short-term opportunities and constraints the resources and capacity for policy debate of each coalition can be better understood. And by differentiating those involved in the policy debate as 'actors', as opposed to those peripherally involved in it, their agency is inferred and their prominence in the debate promoted (Weible & Ingold 2018). Also, by testing its hypotheses,

the ACF can be further developed by either supporting these hypotheses or challenging them. This allows the ACF to become more robust and better able to be applied to future policy analysis research.

## Major Gaps

The major information gaps identified in the literature review are: the precise catalyst for the debate about the delivery of radiotherapy services in the North West and the chronology of the public debate around this; the identity of the main participants from the community in this debate; the exact make up of services that will be offered at the North West Regional Cancer Centre in the wake of the implementation of the One Health System reforms; and the implications of opening the North West Regional Cancer Centre for other, similar services in the state. There also appears to be a contradiction between the disadvantages experienced by people in regional and remote areas and the level of failure to rationalise the services that *are* offered in the North West. While this study may be unable to determine how services will change under the One Health System reforms, or provide a longitudinal study of how the North West Regional Cancer Centre impacts on other services in the state, the remaining gaps will undergo further examination to understand their applicability to radiation therapy services.

## Chapter 3: Methodology

Chapter 1 provided a comprehensive summary of the recent prevalence and incidence of some cancers in Tasmania, as well as the associated issue of modifiable risk factors that are prevalent in North West Tasmania. This demonstrated that the issue of cancer required an appropriate policy response and posed the question of whether the decision to establish the North West Regional Cancer Centre was the appropriate response, with particular consideration of the lower distances travelled by Tasmanian patients. Chapter 2 summarised the most relevant and recent literature on cancer services and policy reform in Tasmania, as well as the main theoretical framework to be used – the ACF. The purpose of this chapter is to describe the methods that were used to gather data and literature beyond the Literature Review and how this data has been analysed.

### Research Need

Chapter 2 highlighted that there was a perceived community need in North West Tasmania for more localised radiation therapy services and discussed many of the issues experienced by those accessing these services from remote locations. There was also discussion of literature indicating that residents of North West Tasmania still fare well in comparison to some mainland counterparts when it comes to accessing services. It also highlighted the unique nature of Tasmania's political system that has facilitated much discussion and commitment to the provision of such services since 2000, especially the newly constructed North West Regional Cancer Centre. However, much of this commitment was counterbalanced by ongoing attempts to reform the health care system in Tasmania. A struggle and tension became evident between the level of services desired in the North West of Tasmania and the structure of services that could be viably delivered. There is, therefore, a clear need for research to determine the impetus, logic and viability of radiation therapy services and options delivered to the North West, and the interplay between the perceived needs of the local community and the attempts at cancer service delivery and reform by the Tasmanian government.

In order to determine how this interplay between community expectations and government policy agendas has manifested, the ACF was applied to the analysis of the issue and its actors. Coalitions were identified, belief systems attributed to each, and a history of action by each coalition built to determine policy-oriented learning, core and secondary beliefs, strategies for promoting policies and the resources of each. Language and narratives were also examined to determine how this has been used as a tool to sway opinion or support for policy proposals.

## Research Aim

The question to be answered by this research is how policy changed to the perceived need for a local radiation therapy service in North West Tasmania, and the motivations behind such public policy changes. This research aim focuses particularly on the policy change that resulted in the establishment of a local radiation therapy service in NW Tasmania. This problem is worthy of research and discussion as it poses the question of why and how policy change is achieved. The establishment of the local service marked a significant change in the current service delivery model and policy analysis would suggest that this change must have been preceded by some motivation or impetus. To understand the impetus for this change is the better understand that nature of policy change, which helps to understand further the policy process.

This research aim will be examined using the ACF to determine which coalitions have been involved in the debate about the establishment of radiation therapy services in the region, what the main policy objectives and beliefs of each coalition have been, and how the interplay between these coalitions has affected the policy outputs and outcomes. Analysis of this interplay, using document analysis and interviews with stakeholders, patients and family, will allow the ACF and its associated hypotheses to be tested and analysis to be made of the major factors that drive policy in this area. An understanding of this will allow policy change to be explained in part.

## Design and Data Collection

This research used a descriptive case study approach, using two data sources: documents and semi-structured interviews (see Figure 5). The case study was the debate over the introduction of radiation therapy services into the North West and the subsequent establishment of the North West Regional Cancer Centre. Document analysis and interviews with stakeholders, patients and family allowed the major advocacy coalitions to be identified and categorised as well as a chronology of key events, such as changes to service delivery or major health reforms, to be established. Document analysis allowed stated viewpoints to be traced over time and checked for consistency. The interviews with patients and family had the added benefit of integrating patient views into the data. 'Experts and stakeholders provide essential technical input but their role is distinct from that of the citizen and cannot replace it...Policy needs to be informed by 'unorganised' citizens, as well as powerful 'organised' interest groups' (Maxwell, Rosell & Forest 2003, 1031).



**Figure 5 Data Collection Sources**

### Document Analysis

The first form of data collected was publicly available documents. Analysis of publicly available documents produced over a given period of time allows the researcher to examine policy change and coalition activity during that period. Additionally, it allows any changes in beliefs, in the form of stated beliefs and policy objectives, to be noted because of the representation of those beliefs over time in documents.

The level of radiation therapy services offered in each region of Tasmania has been an issue of considerable public debate over many years and resulted in many attempts at restructuring and reforming current service levels and design. As discussed in Chapter 2, there have been a minimum of five major attempts at health reform in Tasmania since 2000, and the delivery of radiotherapy services in North West Tasmania has featured prominently in at least two federal election campaigns (2007 and 2010). This indicates that there existed considerable scope for data collection within policy documents and associated grey literature.

## Research Design and Approach

Good research is achieved through rigour. Rigour is assessed through the attainment of reliability, validity, quality and credibility of data collection and data analysis (National Health and Medical Research Council 2015). Reliability refers to the design of the study and data collection. It relates to the extent to which the results of the research study demonstrate consistency over time and the capacity for the results to be reproduced under a similar methodology (Golafshani 2003). Validity determines how well the research has measured what was intended and how truthful the results are in considering any impacts that could alter the results (Joppe n.d.), such as sampling bias. Quality in qualitative research has the purpose of generating understanding and without quality an understanding of the field of inquiry is diminished (Stenbacka 2001). Finally, credibility refers to the congruity between the results derived from a research study and reality (Merriam 1998). It is considered to be one of the cornerstones in establishing trustworthiness in research (Lincoln & Guba 1985). If these are achieved then rigour has been attained.

Document analysis was used to construct and identify the members of advocacy coalitions involved in the policy debate over radiation therapy services in North West Tasmania, their beliefs, interests and policy positions. Members are better identified by document analysis over a given period of time than by a cross-sectional analysis as such documents serve as a record of participation by a consistent set of members in a single subsystem over that period (Jenkins-Smith & Sabatier 1993). Document analysis also offers greater reliability than surveys or interviews alone as it is shown that participants in the debate are less likely to alter their position or beliefs to fit their audience when tracked across a longer period of

time or when representing their coalition in a formal setting, such as a parliamentary hearing. This prevents damage to the consistency of the coalition's message (Goggin cited in Jenkins-Smith & Sabatier 1993). Reliability is further enhanced as document analysis offers the author greater capacity to set the scope of what will be discussed and in what order, which might be limited in an interview setting.

## Procedure for Data Collection

Documents were derived from a variety of sources, both electronic and physical. Databases (EBSCO and ProQuest) were used in conjunction with Google Scholar, Trove, the Tasmanian Archives, the University of Tasmania thesis depository, the Launceston General Hospital Library, the Buttfield Library, and citation searches.

One of the key initial steps in content analysis of documents to explore beliefs, objectives and changes over time is to identify the relevant target population from which a sample can be drawn and coded (Jenkins-Smith & Sabatier 1993). Once this is known, documents can be more readily sourced as they will come from government documents and documents relating to the interest groups involved. The target population in this instance was the health service, North West regional representatives, health professional representatives, patients, families and consumer representatives.

Literature was sourced by returning to the two searches conducted for the Literature Review (see Figures 1 and 2) and drawing the most relevant documents from those results, as well as an additional manual search. While the first two searches in the Literature Review covered a range of issues that established the context for the research, the documents required for Results needed to be specifically focused on radiation therapy services in North West Tasmania and those issues directly impacting on the research focus. Documents were screened to determine whether a belief of a coalition was expressed that might add to the mapping of the policy subsystem. Very few of the documents left retained reference to the ACF as this had not been applied to a Tasmanian health context in more than a few instances.

The type of literature selected from the initial two searches included journal articles, federal government reports and documents (including the Department of Health, Australian

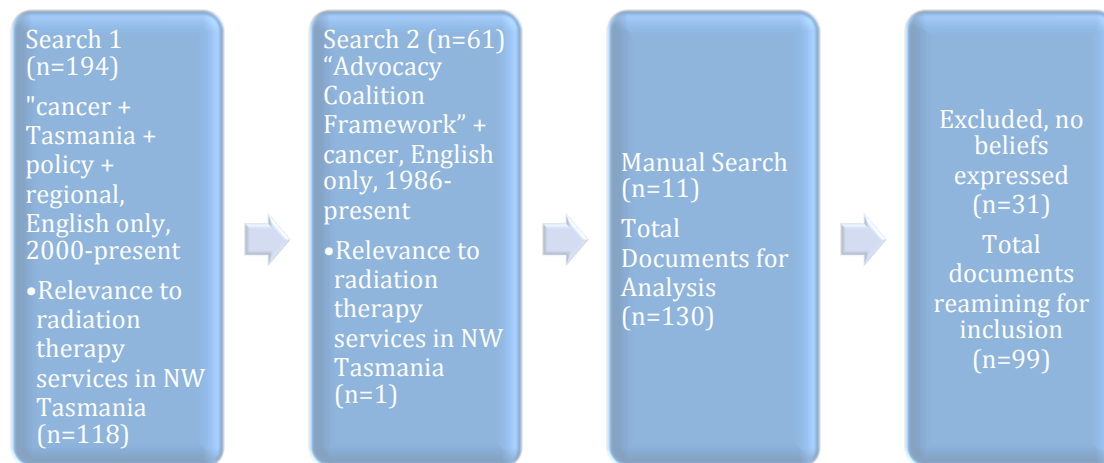
Institute of Health and Welfare, Australian Bureau of Statistics and Cancer Australia), Tasmanian state government reports and documents (including Department of Health and Human Services), Hansard (both Commonwealth and Tasmanian), reports by non-government organisations involved in the health care field, media articles, policy documents, and media releases and statements made by candidates, representative bodies and other stakeholders.

The only additional search conducted was for Letters to the Editor to specifically address the beliefs of the general public over the course of the policy debate, as this had not been covered in any significant detail in the documents found for the Literature Review. This was noted to be a gap in the documents found thus far and was addressed through a manual search. This search created a limitation in the data collection process related to the search of the local newspaper, *The Advocate*. The website of this paper had no capacity to sort by date or category (Letters to the Editor) and yielded results unrelated to the search terms. When a direct request was made to the paper the response was that there was no way to search the Letters to the Editor exclusively without going through each paper individually using microfilm. A search was then conducted using the NewsBank platform, however the category of 'Letters' with *The Advocate* only commenced in June 2014, which fell outside the peak period of interest in the lead up to the 2007 and 2010 federal elections. A search of *The Advocate* using ProQuest with the inclusion of 'Letters' as a category was also limited as these records only date back to July 2011. The results produced did not identify any information pertinent to the research. This meant the key period of time pre-2010 in this particular newspaper could not be practicably searched for public opinion and requests to the newspaper to access historical 'Letters' confirmed that the newspaper did not have this function available.

The result of the revising of the documents collected for the Literature Review and the additional manual search for Letters to the Editor resulted in a total of 130 documents that could be used for document analysis (see Table 8). From this, a further 31 were excluded as they did not express what could be considered a belief, leaving 99 documents for inclusion in the document analysis.



**Table 8 Process for selecting results from combined searches**



Abstracts of articles and Executive Summaries of reports were read to confirm if the contents related to: cancer treatment rather than screening; services in Tasmania, another Australian state with some applicability to Tasmania, or internationally with strong applicability to the research question; health policies at a Tasmanian or federal level that impacted on radiation therapy services; policy commitments by candidates or elected representatives; statistics relating to incidence or prevalence of cancer or modifiable risk factors in Tasmania and/or Australia; funding arrangements between cancer service providers, namely the Tasmanian state government and federal government; changes in the current levels of cancer service delivery or design; calls from prominent stakeholders or local communities for changes in current cancer service delivery or design; services provided in the public as opposed to private health system; and finally the application of the ACF to the field of cancer services policy, with particular emphasis placed on those from an Australian context.

## Data Analysis

When a set of documents resulted from this process of inclusion and exclusion, each document was read, re-read and its contents coded using NVivo qualitative coding software according to the range and level of beliefs expressed, to determine what might be considered the deep core beliefs, policy beliefs or secondary beliefs (See Appendix 2). As the

documents represent an expression of these beliefs over time they can be coded according to the degree to which they changed and for which audience they might have been changed.

Deep Core (DC) beliefs are defined as fundamental normative and ontological axioms that form part of the person's basic philosophy (Jenkins-Smith, Nohrstedt, et al. 2014). These are resistant to change and involve the priority of values such as freedom, health, knowledge and security as well as whom they see as the priority. Importantly, these concepts would apply across all policy areas and not be exclusive to the policy area or subsystem in question.

Policy Core (PC) beliefs are described as those basic strategies designed to achieve the DC values and apply to the policy area in general, as well as possible application to other areas. This level of belief is bound by scope to the policy subsystem in question, meaning that a person may believe one thing in regard to one topic but have a different view when the same issue is applied to another area (Jenkins-Smith, Nohrstedt, et al. 2014). It covers such issues as the proper scope of government, the distribution of authority, the identification of which groups are most affected by an issue, the magnitude of the perceived threat, and choices between policy instruments.

Secondary Aspects (SA) were those that relate specifically to the policy subsystem in question and relate to the means by which PC beliefs can be achieved. These include issues relating to the administration or resources of the issue or the perceived performance of the programs involved.

### Advocacy Coalition Framework

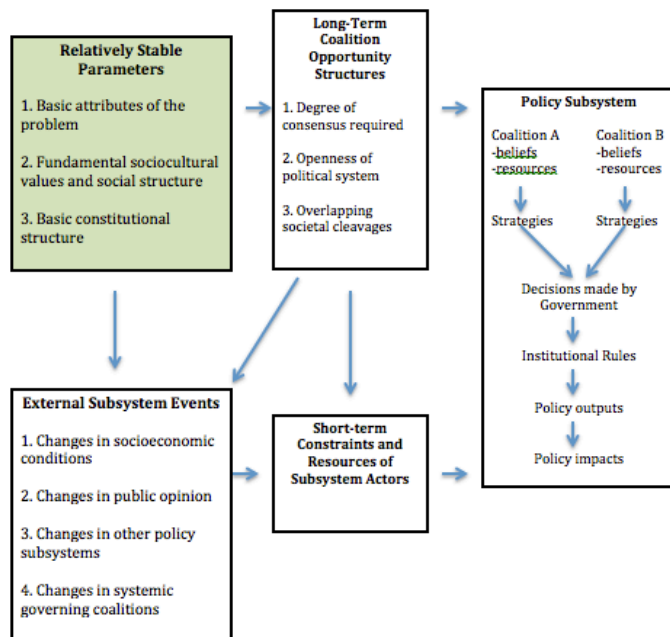
The ACF is used as the policy analysis tool. The framework centres policy debate on conflict between advocacy coalitions. These coalitions are bound by a common set of beliefs and values and can include a broad range of actors, from politicians and bureaucrats to community groups, consumers, researchers and professional bodies. These common beliefs and perceptual filters can alter the way in which the same information may be processed and set views reinforced, such as the right to universal health care or the need to keep major services centralised (Sabatier & Weible 2007). Such entrenched perceptions do well to explain why there is always ongoing policy conflict.

Under the ACF, policy change takes place amidst policy sub-systems which, while bound by relatively stable parameters, are still able to be impacted by major external events (Weible et al. 2011). These external impacts combine with the long-term opportunities and short-term constraints faced by sub-system actors to produce the Policy Subsystem – the realm within which coalitions interact and implement strategies to influence government decisions and institutional rules. These rules create authority and result from competition between coalitions, indicating that influence over rules can create further authority or power for the influencing coalition (Sabatier 1988). The results are the policy outputs (government decisions) and policy impacts (the way a policy change impacts on coalitions and their policy objectives) (see Figure 3).

The ability to generate change from within the Tasmania health policy subsystem is largely constrained by the national division of powers associated with federalism and the statewide political competition associated with the Hare-Clark electoral system (Shannon 2009, 58).

The level of radiation therapy services to be offered within the North West of Tasmania, or to be offered to those from the North West, constitutes a specific policy subsystem. Within it have been a range of major actors, including the federal government, state government, media, individual community members and representatives of the medical and health professions – debating the merits, need, and sustainability of local as opposed to centralised services. Some actors expressed concerns over the cost of extending services, the primacy of patient safety, and the lack of critical mass in the North West to support such a service and attract and retain appropriately qualified specialist staff. Others highlighted the impact of travel on cancer patients and perpetuated a highly regionalised view of service provision within the state.

Each element of the ACF examines factors that impact the end result – policy outputs and policy outcomes – in this case the level and design of cancer treatment services available to the North West Tasmanian population.



**Figure 6 Relatively stable parameters**

The first structure of the policy subsystem is the relatively stable parameters. By nature, these attributes are rarely the catalyst for change but instead establish the resources and constraints of participants (Sabatier & Weible 2007).

The first such parameter is the **basic, immutable attributes of the problem** that lies at the heart of the policy debate. In this context this can be defined as the realities of the disease, the realities of providing health services and the realities of living in regional and remote areas.

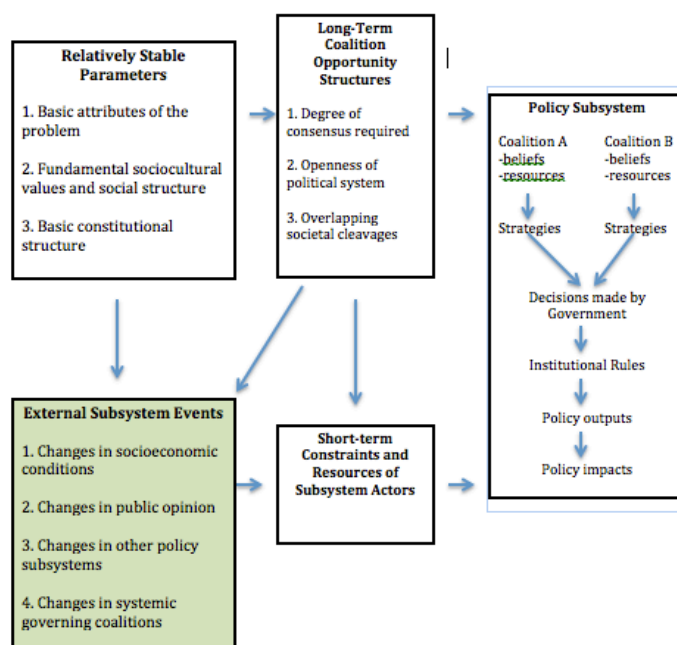
The **distribution of natural resources** involves society's wealth and the way in which these resources impact on economic sectors, culture and the financial viability of different options (Sabatier 1988). In the context of the policy debate over radiation therapy services, this is largely reflected in Tasmania's geography and demography and its economic capacity to fund health care.

The fundamental **sociocultural values** and social structures are an important impact on the policy subsystem as they shape public perceptions and political resources. Palmer and Short (2014) accurately reflect Australian societal values when they stated that properly publicly

funded health and reducing the burden of health costs on the individual are part of a developed society. Indeed, the provision of public health at a level deemed acceptable by the public is a cornerstone of politics and policy.

The **basic constitutional structures** provide the grounds for political and legal change. In the context of radiation therapy services, this relates largely to funding arrangements for health, as well as Tasmania's unique political system generated by the Hare Clark voting system and Tasmania's regionalised nature.

Health has been internationally, but not uniformly, acknowledged as a universal human right, bringing it above the status of mere policy (Keleher & MacDougall 2016) and this has implications for the way society expects it to be funded. The main role delineation between the Commonwealth, states and territories is the former as the funder and the latter as the providers (Council of Australian Governments 2012). Agreements between states, territories and the Commonwealth aim to provide comprehensive and equitable access to health care and information relevant to their health needs and support services (Council of Australian Governments 2012).



**Figure 7 External events**

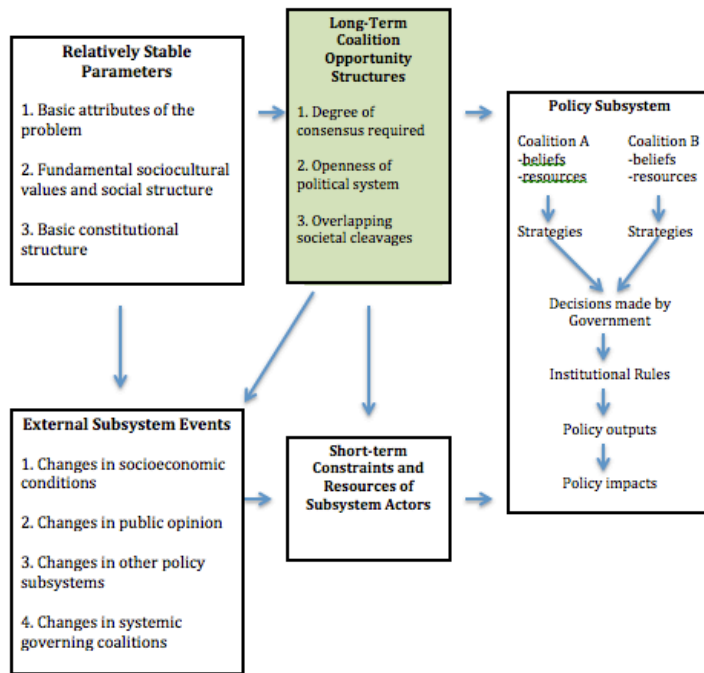
**External system events** represent changes in the core attributes of the subsystem brought about 'by shifting and augmenting resources, tipping the power of coalitions, and changing beliefs' (Weible, Sabatier & McQueen 2009, 124). The unpredictable and often far-reaching nature of such events means they are often the catalyst for policy change. As outlined in Chapter 1, this research looks at external events from 2000 onwards as part of the overall influence on the policy subsystem.

The Global Financial Crisis and the drop in commodity prices seen in Australia are two such **changes in socioeconomic conditions** that have impacted on the capacity to deliver radiation therapy services in North West Tasmania. It is important to note that with the introduction of the GST in 2000, Tasmania's health budget actually increased, rising 17.4% in three years (Duckett et al. 2002). However, this increase to health spending is threatened by repeated calls for a recalculating the GST distribution formula.

**Public opinion** is a formidable tool in driving policy change, whereby windows of opportunity can be created for public sentiment to build in support of a policy proposal. In the instance of radiation therapy services in North West Tasmania, particular focus is paid to public opinion to understand its role in policy change and whether it was a formidable tool.

**Changes in governing coalitions** have the capacity to move focus and open opportunities in the policy subsystem. Changes and attempted changes in governing coalitions are also of particular note in this case study and are used as markers to divide events into discrete time periods to understand policy change.

**Impacts from other subsystems** can be difficult to identify because of the breadth of subsystems and the direct and indirect means by which they might impact the policy subsystem. Subsystems never operate in isolation and impacts from other subsystems are one of the most likely causes of dynamic shift in a policy subsystem (Sabatier 1988).



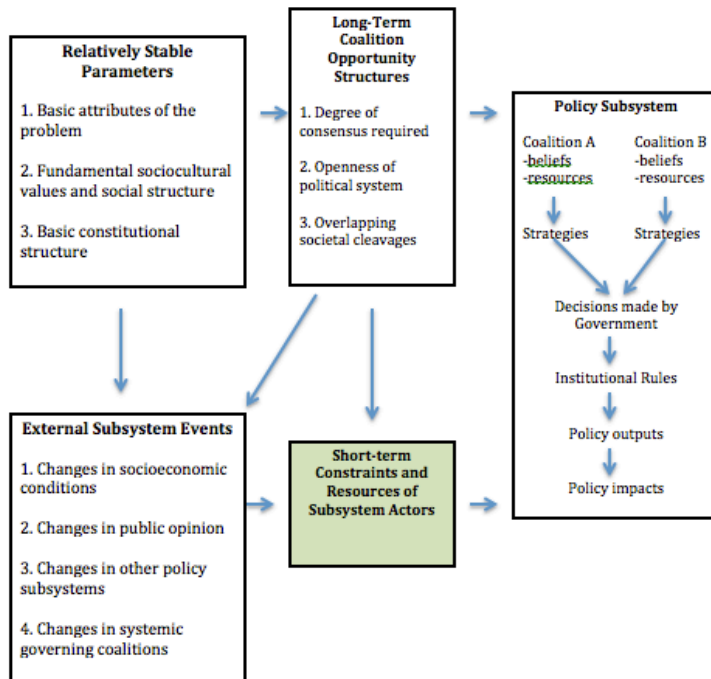
**Figure 8 Long-term coalition opportunity structures**

The shape of the political system through which policy change is achieved, and the societal forces that impact this, is a long-term structure that may help or hinder proponents of change.

**Overlapping societal cleavages** represent the ‘accumulated impact of social, economic, ethnic, religious divides within society. The greater the overlap, the higher the risk of conflict...’ (Shannon 2009, 51).

The **degree of consensus** needed for policy change highlights the density of coalition membership and therefore the strategies that will need to be employed to achieve change (Weible, Sabatier & McQueen 2009). The more consensus needed the more inclusive coalitions will become.

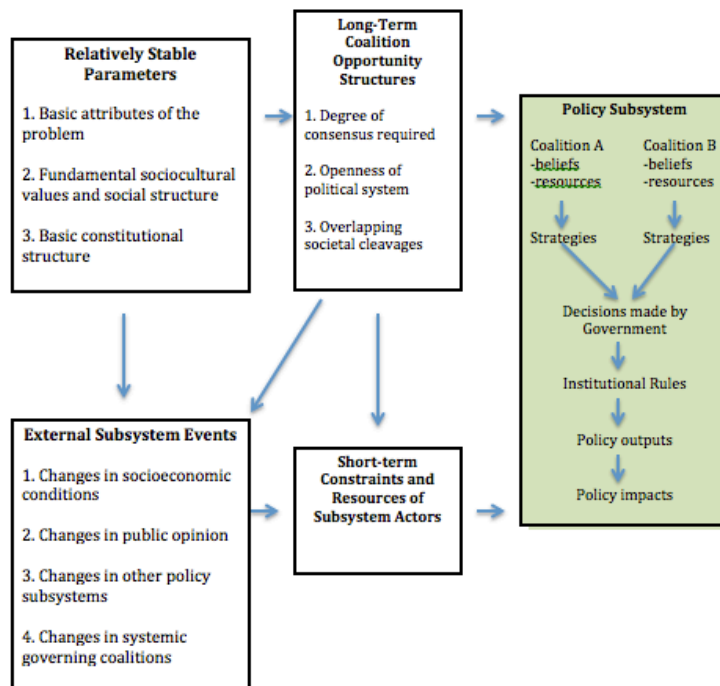
The **openness of the political system** in which the subsystem operates points to the number of decision-making forums and checkpoints a proposed policy change would need to pass through.



**Figure 9 Short-term constraints and resources of subsystem actors**

The original flow chart for the ACF does not list any specific subcategories under ‘short-term constraints and resources of subsystem actors’. Whether prescriptive subcategories of resources and constraints are required to further develop the framework needs to be considered.





**Figure 10 Policy subsystem**

What remains is the subsystem – a meeting of coalitions in debate over the best way to address societal issues through policy, in this case one hypothesised coalition for increased local provision of radiation therapy services and the other against it or at least cautious of the extent of it.

Cancer services in North West Tasmania was determined to be the policy subsystem, rather than the broader delivery of health services, in order to fit with the definition of the ACF. Policy subsystems have been defined within the ACF as being semi-autonomous partitions of a broader system (Weible, Sabatier & McQueen 2009). They have a topical focus and a ‘geographic scope’ (Weible & Ingold 2018, 329). Partitioning is considered an appropriate approach to defining subsystems (Weible Sabatier & McQueen 2009) and one policy subsystem can be nested within another larger subsystem (Weible & Ingold 2018), such as cancer services in a regional area sitting within the larger health system as a whole. This subsystem was considered separate from the wider health system for two reasons: the regional nature of the subsystem and the subsystem-specific nature of the disease, its treatment and the actors within it.

The regional nature of the subsystem is derived from the fact that health services within a regional area are very different to those delivered in a metropolitan area. Tasmania has been recognized as a state that demonstrates strong localism (Crowley, 2000), something which has often rippled through to the regional provision of health services, even when these struggle to achieve critical mass (Shannon, 2010). This localism has been evident in numerous attempts by State Governments to repurpose or downgrade services available in regional areas in order to achieve greater efficiency and quality of care, which have been met by strong regional resistance. Therefore the discussion of a cancer service in NW Tasmania remains distinct to the discussion of cancer services state-wide as the sense of localism and the affect of travel and accessibility to regional patients makes these two types of service delivery very different, resulting in different actors with different policy beliefs relating to them.

The second distinction in regards to this subsystem is the difference in actors, treatment and the nature of the disease. The framework, whilst acknowledging that the subsystem is influenced by wider policy impacts, states that the policy subsystem will be defined by its relatively stable parameters and that the policy beliefs of coalition members will be specific to that subsystem (Sabatier & Weible 2007). As each aspect of health will have different relatively stable parameters, it follows that the policy beliefs will also be different. The basic attributes of the problem related to heart disease and access to appropriate treatments and services will be different to the basic attributes of the problem relating to cancer services. One may relate more to basic attributes of modifiable risk factors and may involve treatments that are more easily delivered at a local level by mainstream health professionals. Obesity in adults will be viewed differently, and given a different priority, to the treatment of cancer patients. One may involve more education and dietary advice while the other may involve a more onerous treatment regime with more significant side effects and impacts. In addition, the range of actors will vary between different aspects of the health system. The participants included as part of the data collection in this study specialized largely in the area of cancer services or advocacy for these services in NW Tasmania. Medical professionals specialized in certain areas of health and will often only involve themselves in policy beliefs that reflect these specialized areas. The non-health participants were also only concerned about the delivery of cancer services, and their policy

beliefs in regards to other aspects of health, such as neurosurgery, may have varied greatly from their beliefs relating to cancer services. This creates a unique policy subsystem, with unique basic attributes that lead to specific policy beliefs of specific coalition members, making cancer services in the North West of Tasmania the appropriate definition of a subsystem.

Each coalition uses its shared beliefs to guide its strategies but the resources of each coalition largely influence these strategies. Sabatier and Weible categorised these resources into six groups: formal legal authority to make policy decisions, public opinion, information, ability to mobilise troops, financial resource and skilful leadership (cited in Weible et al. 2011).

The government of the day is clearly dominant and has the formal legal and constitutional authority to make policy decisions. However, elections have proven an opportune time for consumer advocates to shape public opinion and mobilise troops, a strategy that is often utilised by coalitions that lack financial resource. And the more public opinion moves behind one position, the greater the likelihood that they will elect a government that reflects their views. Governments, particularly the federal government, hold the majority of the financial resources, however public opinion will often dictate how these resources are directed. Conversely, financial resources can be used to gather credible expert opinion or information that can shape public opinion. The result is a mix of skills and resources that are utilised by each coalition to achieve maximum effect on policy outputs and outcomes.

### *Quality and rigour of design, data collection and analysis*

The quality, validity and reliability of the scholarly and grey literature obtained were strengthened by clearly defined inclusion and exclusion criteria (see Appendix 1). This ensured that information was gathered and assessed in a consistent and predictable manner. The adoption of a theoretical framework, the ACF, prior to data collection, also further strengthened rigour as it allowed for a consistent meaning and significance to be placed on information according to the theory being used (Yin 1994).

There can be concerns about the validity of public statements, where the subject can alter their beliefs to fit the audience rather than giving a true opinion. An advantage in public

document analysis is that the propensity to alter one's beliefs diminishes as the message moves from the general public arena to a narrower elite forum (Goggin cited in Jenkins-Smith & Sabatier 1993). Many government documents and interest group statements made in relation to the policy subsystem are designed for a specific and elite audience, and inconsistency in the message delivered would harm credibility. Equally, validity is served by being able to track the publicly available statements of subsystem actors over time, and thereby pinpoint consistency or changes in beliefs.

All coding of document analysis data in NVivo was created and cross-checked by all members of the Research Team, including the supervisors and the Doctoral candidate. This ensured that no systematic error was included in the creating of codes (nodes) in NVivo by a single coder.

## Interviews

### Design, Rigour and Quality

The second form of data used was face-to-face, semi-structured interviews with stakeholders, patients and family. Stakeholders included employees of the public health system or government departments or agencies associated with the public health system, elected representatives, representatives of health professional bodies and non-government organisations and community identities.

Stakeholders were considered relevant for data collection due to their work in delivery, design or advocacy of cancer services in Tasmania. Their contribution to policy change was therefore considered possible and relevant to answering the research question.

Patients and family members were also considered relevant for the purposes of data collection as the ACF works explicitly on the assumption that there are two or more coalitions vying for influence in the policy subsystem. Over recent decades there has been an ever-increasing number of policy documents that promote involvement of patients, consumers and the general public in health policy development, consistent with the role consumer groups have wished to have within the policy process (Australian Commission on

Safety and Quality in Health Care 2008; Department of Health 1996, 1998). As a core interest group in the subsystem, it was reasonable to consider that patients may either form a part of one or more coalitions or that their insights might help to identify possible coalition members.

Health consumer groups could have been another possible avenue for interviewing and data collection. These groups are now extensively involved in the policy-making process through lobbying efforts and media campaigns and have met the growing push for consumer engagement by being representative of patient groups as a whole (Jones, Baggott & Allsop 2004). Health consumer groups have been considered as one remedy to the apparent lack of interest of consumers in health policy in comparison of professional and policy groups (Jones, Baggott & Allsop 2004). However, in this case study this particular subset of patients was not directly represented by an identified health consumer group. No organisation that directly represented the needs of cancer patients from the NW was identified. This meant directly interviewing patients was the only direct way in which to gauge consumer interests.

Patients, as direct users of the cancer services system, were logically identified as those with a vested interest in the design and delivery of cancer services and were therefore close enough to the issue to have relevant information on policy change. Additionally, the patient experience is impacted by the quality of the relationships developed during their involvement in the health system, with health policy as part of this system. It is these relationships that support service delivery but are also integral to the broader value that society places on the health system (Gilson 2003). Therefore, understanding the experience of patients helps to understand the value that they, as part of society, place on the health system.

In-depth and semi-structured interviews explore the experiences of participants and the meanings they attribute to them. Researchers encourage participants to talk about issues pertinent to the research question by asking open-ended questions, usually in one-to-one interviews. The interviewer might re-word, re-order or clarify the questions to further investigate topics introduced by the respondent. In qualitative health research, in-depth interviews are often used to study the experiences and meanings of disease, and to explore

personal and sensitive themes. They can also help to identify potentially modifiable factors for improving health care (Tong, Sainsbury & Craig 2007, 351).

Semi-structured interviews allow data mining from a primary source, for personal experiences, perceptions and feelings to be discussed and for a level of authentic insight to be created that can not be replicated in alternative forms of qualitative research, such as questionnaires (Crouch & McKenzie 2006). It also allows different perspectives to be recorded verbatim to give further strength to Advocacy Coalition analysis.

The semi-structured interview allows for more consistency between interviews than unstructured interviews by preparing a short suite of questions to guide the interview, without being as prescriptive as structured interviews. This can be particularly helpful when interviewing those who are less adept at talking freely (Corbin & Strauss 2015). Flexibility is still achieved, however, by being able to update and replace questions as the interviews progress and more is uncovered about what may be most relevant to the research (Glesne 2010).

The main drawback to this approach, however, is that pre-written questions do not ensure that those issues most important to the participant are covered (Corbin & Strauss 2015). There are also issues of the impact of verbal and non-verbal cues from the interviewer or other people present during the interview, the setting for the interview and researcher bias and assumptions (discussed further in) (Tong, Sainsbury & Craig 2007).

North West Tasmania was the setting for the interviews because of this region being the focus of the policy change in question. Stakeholders were interviewed in their workplaces, unless otherwise requested, to highlight the connection between their work and their involvement in the research. Stakeholders were selected because of their work in or around radiation therapy services and therefore the workplace is the most appropriate venue. Patients/family were interviewed at home, unless otherwise requested, to allow a sense of security and familiarity to the interviewee as well as a degree of privacy when discussing personal issues relating to their experiences (Glesne 2010). Only the interviewee and the Doctoral candidate were present, unless otherwise requested by the interviewee.

Demonstrating an effort towards arranging a convenient time and place for participants demonstrates mindfulness and respect. Choosing a location and time for interviews where participants feel relaxed, safe and private will also increase depth of discussion (Glesne 2010). Therefore it was ensured that patients were able to choose a time that was most suitable and the venue that allowed them to feel safe, comfortable and familiar. Timing considered such aspects as not imposing on meal times or meal preparation, not scheduling interviews to sit adjacent to other time commitments for the interviewee, and not holding interviews at times when the interviewee was likely to be called away or interrupted. Minimisation of distractions was also achieved by ensuring a quiet space, such as a contained meeting room with a closed door. Participants were provided with a preamble to the interview to ensure they understood how their perspectives would be valuable and therefore how their involvement was worthwhile (Frankfort-Nachmias & Nachmias 2008).

### *Ethical considerations*

The National Health and Medical Research Council specifies principles that must be met in research involving human participants in order to ensure ethical considerations are appropriately understood and managed (National Health and Medical Research Council 2015). The four principles of research merit and integrity, justice, beneficence and respect were all incorporated into the research design and data collection.

### *Research merit and integrity*

This principle outlines the conduct that must underpin research in order to provide benefit and further add to collective knowledge.

A full ethics application was made to the Tasmania Health & Medical Human Research Ethics Committee (HREC) (see Approval Letter at Appendix 3), as interviews could involve the discussion of sensitive issues that might cause distress to the interviewee. All material to be used in the recruitment and interviewing of stakeholders and patients were reviewed by the Committee as well as by the Head of the School of Health Sciences at the University of Tasmania. The original submission resulted in a request for further information by the Committee, which was then prepared and submitted before approval was given. A later amendment request was made to the Committee (see approval letter at Appendix 4) to

allow the recruitment sites to be broadened in order to counteract a low initial number of responses to the advertisement for participants. The process of gaining initial approval for ethics took approximately 6 months with a further 6 weeks added for the amendment.

As the interviews necessitated close involvement by the Doctoral candidate with the participants, it was impossible to completely negate the effect of personal bias (Tong, Sainsbury & Craig 2007). Therefore all data, analysis, coding and themes derived from the interviews were checked by the three supervisors to ensure reliability.

### *Justice*

The principle of justice mitigates burden and exploitation of participants in the research and fosters fairness.

Patients/family were recruited via an opt-in system. This avoided any concern relating to dependent relationships. If doctors or health care coordinators approached patients or families with a direct invitation some participants may have felt influenced by the patient/health professional relationship and there was potential for them to feel compelled to consent (Comstock 2012).

### *Beneficence*

Beneficence is the principle that the research must do good and minimise harm or risk to those involved in the research. As this research involved people who had experience or exposure to a life-threatening illness there were risks that needed to be considered.

Interviewees were provided with an Information Sheet (see Appendix 5) and Consent Form that outlined the nature of the research and participation, as well as details of support services that could be accessed if required. Interviewees were also reminded at interview and in the Information Sheet that they could request to postpone, cease or cancel their interview at any time. Potential influence on the outcome of the interview was also minimised by excluding any participant who was known to the Doctoral candidate.

Interviews were conducted at a venue chosen by the interviewee to ensure the greatest ease and comfort of the interviewee and were audio-recorded and transcribed. Copies of the transcript of interview were provided to those who requested this to ensure that the



transcripts accurately reflected their views. Interviewees were able to request that the transcripts be altered up to 4 weeks post-interview. Interviews were not transcribed verbatim but rather transcribed to accurately reflect what they had said and its intent.

### *Respect*

Respect recognises the intrinsic value of people and ensures that research promotes autonomy and supports a person's own identity. A key part of respect is the maintaining of privacy. Confidentiality was maintained by replacing all names with an alphanumeric code. Information linking these codes back to the interviewee's name was stored on a password-protected file on a password-protected laptop that was only accessible by the Doctoral candidate. Stakeholders were asked to consent to the inclusion of their role and organisation's name in order to provide context for information given and it was made clear to the stakeholders and patients in the Information Sheet and Consent Form that because of the small size of Tasmania it was possible that people might be identifiable to some readers.

### *Sampling and recruitment*

The aim of sampling in qualitative research is to identify specific groups of people who hold characteristics or live in circumstances relevant to the phenomena being studied (Al-Busaidi 2008, 14).

Proper sampling can ensure that a breadth of experiences and perspectives are captured and analysed, rather than simply looking at those most frequently experienced among the wider population, thereby encouraging an analysis that reflects the diversity of experiences (Ziebland & McPherson 2006).

Data saturation refers to a point in time where continued sampling results in no further new information being obtained (National Health and Medical Research Council 2015). This may be achieved via a relatively small sample or may require a more substantial sample, which is determined by the nature of the research study. Guest et al (2006) posit that the more similar participants are then the fewer interviews or surveys that will be required to reach data saturation and that purposive sampling often leads to homogenous samples. Ziebland and McPherson (2006), however, believe that there is no formula for knowing when

saturation can be achieved but rather it is evident when saturation has *not* been achieved, as evidence is thin. Whether homogeneity is a good attribute to have in recruitment or not will depend on the nature of the research question. In this particular research, a homogenous sample was not an aim as a breadth of participants, covering all stakeholder areas, was required.

The total sample size was 38 participants. This constituted 15 stakeholders (including two who consented to an interview but did not want their identities or responses included in the findings) and 23 patients/family (see Table 9). Stakeholders were sought and interviewed until all key advocacy coalitions were identified as much as practicable and no new ideas were generated from these interviews. Whether data saturation was achieved was considered secondary to ensuring that richness of data collection was achieved during the interviews. Richness refers to achieving results that provide depth and breadth of information (Glesne 2010). This achieved through using questions that ask for an expression of experience, opinion, value, feelings, knowledge and sense, as well as ensuring data is collected at a time and place that promotes comfort, confidence and privacy and providing active listening.

**Table 9 Interview participant by profession or patient status**

Stakeholders (n=15)	
Medical Professionals	4 (3 oncology specialists and 1 GP)
Elected Representatives	2
Community Advocates	5
Health Bureaucrats	2
Undisclosed	2

Patients (n=23)	
Patient	17
Family Member	6

As semi-structured interviews were done with patients, the sample size of 23 patients/family was deemed appropriate in order to facilitate a close association with the interviewees and enhance the validity of in-depth inquiry (Crouch & McKenzie 2006). While the interviews focused on personal experiences, and thereby were less focused on reaching data saturation, codes and themes could still be derived and therefore a small sample size was applied for the same reasons as the stakeholder cohort.

This process began in February 2016 (see Table 10) after ethics approval was received. Stakeholder interviews commenced shortly after recruitment commenced in Feb 2016 and concluded in October 2016. Stakeholders were recruited using snowball sampling and a direct letter of invitation to participate in an interview. Snowball sampling involves prior participants recommending future participants for interview, which can be helpful when the researcher does not necessarily know all the participants who could be included (Marshall & Rossman 2006). This is also known as ‘reputational sampling’, where policy elites nominate other policy elites until no new names are given (Jenkins-Smith & Sabatier 1993). The selection of stakeholders was, in part, theoretically derived based on the ACF and such participants represented key figures in what was initially thought to be the main coalitions

or advocacy groups involved in the policy subsystem. The limitations of this approach include the reality that some stakeholders might not be identifiable through snowball sampling or a review of relevant grey literature and therefore their involvement goes unrecognised.

Stakeholders were interviewed first as these people were identified through the literature review and could be directly approached as invited for an interview. No delay was required to first advertise then respond to expressions of interest. A deliberate decision was made by the Doctoral candidate to interview most stakeholders first (at least those initially identified) before commencing the recruitment and interviewing of patients as there was a single person conducting these interviews and focusing on one group at a time via letters of invitation allowed for better control of interview numbers than open advertising for participants. Stakeholder interviews were also conducted across the state, making this aspect more time consuming, giving greater merit to the rationale to deal with a majority of the stakeholder interviews first, then moving on to the patient interviews.

Purposive sampling was used when recruiting patients and family members for interview as the interviews aimed to describe this particular subgroup in depth, rather than using wider sampling to gain a broader range of experiences (Al-Busaidi 2008). Purposive sampling involves the selection of participants according to predetermined criteria that are relevant to the research in question (Guest, Bunce & Johnson 2006), in this case patients from one region with one common diagnosis. Patients and family were recruited via an opt-in system with an advertisement in local newspapers, posters and fliers in the North West Regional Cancer Centre, regional Community Health Centres and support services, such as Cancer Council Tasmania. There was no direct approach to patients/family. Patients and family were defined as past or present cancer patients over the age of 18 who resided in North West Tasmania at the time of diagnosis or their direct family who had a carer role in relation to the patient, such as a parent of a patient (whereby the patient might be under 18 years) or spouse. The limitation of this approach is that it relied on patients to be aware of the call for participants and to opt in to the research. This may have resulted in patients of a particular disposition being more readily inclined to participate or those with the strongest grievances or issues with the current system wanting an opportunity to discuss these. Mitigating this was achieved by placing posters in high visibility public areas that were most likely to result

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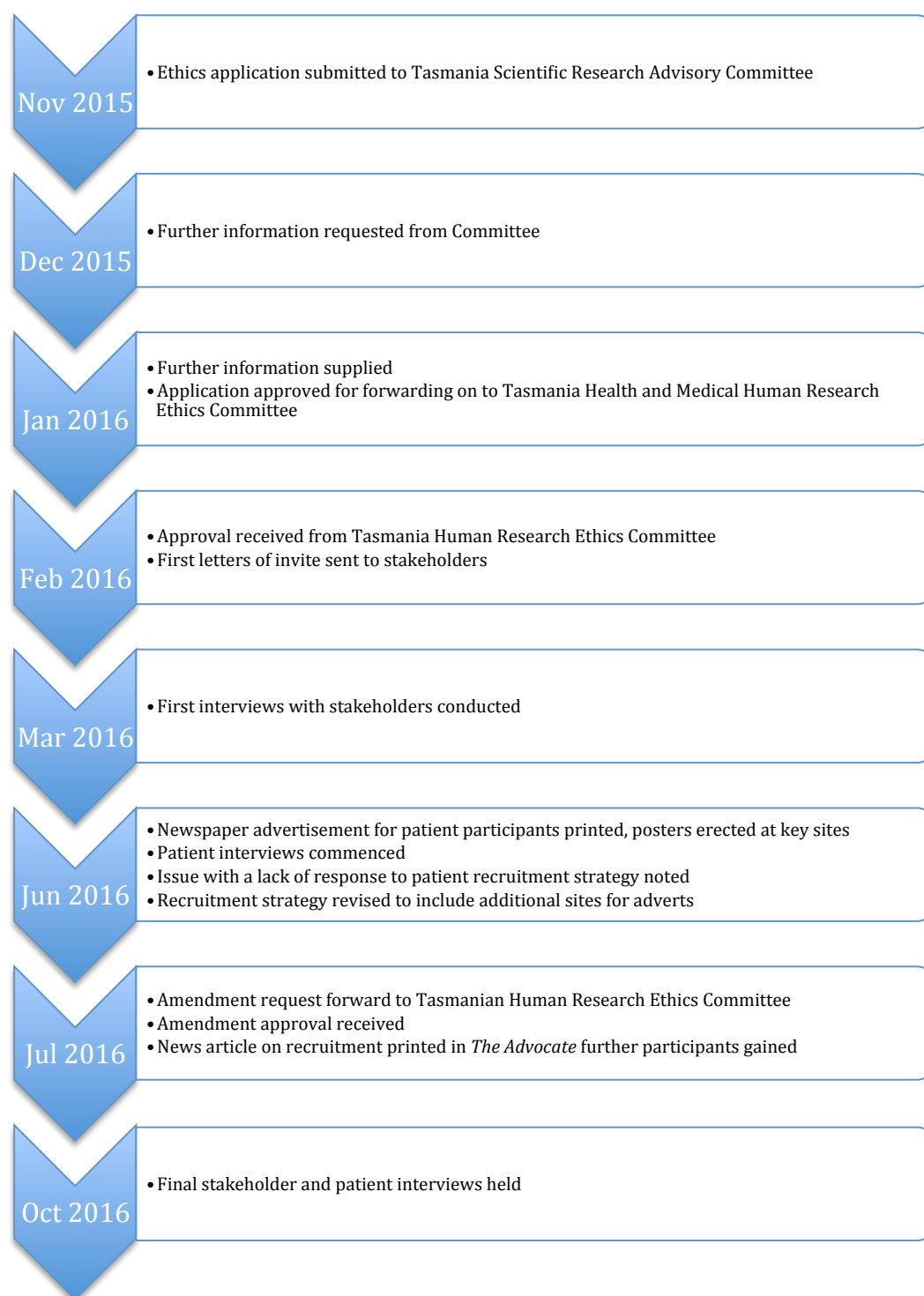
in suitable participants seeing them. Controlling who then expressed interest and their motivations for participation could not be achieved except for use of the exclusion criteria mentioned previously.

Initial advertising strategies were commenced in June 2016. However, the first attempts at recruiting patients resulted in only three interviews. As a consequence, the recruitment advertising strategy was reviewed and further options for locations (including online newsletters of health organisations) and methods by which to promote the study (namely attendance at cancer events) were discussed. An amended ethics application incorporating these new ideas was submitted in July 2016 and approved in the same month. In July 2016 details of the recruitment were sent via email to the local newspaper and a request was made to print the details as a community interest story. This appeared in early July and an increase in participant enquiries was received after that time. Patient interviews commenced in June 2016 and concluded in October 2016. The timeframe for recruitment is discussed in Table 10.

### *Data collection procedure*

Interviews using semi-structured questions and additional prompts were used when talking to patients, family, and stakeholders of cancer services in Tasmania (not all patients had received radiation therapy). Basic demographic information was not considered relevant to the information sought (experiences as opposed to gender or work status) and was therefore gained through observation rather than a demographic information sheet.

**Table 10 Timeframe for recruitment of interview participants**



Interviews were done face-to-face with both stakeholders and patients, and were audio-recorded. Interviews were then transcribed and a transcript was offered and made available to participants who requested this to ensure the transcription of interview accurately reflected their views. Interviews were not transcribed verbatim, however key points and

statements were accurately transcribed to reflect the information provided and its intent. In addition, extensive field notes were taken. While not verbatim, interviews were analysed to note where particular words or phrases were used on multiple occasions, where the participant demonstrated heightened emotions or when a strong sentiment was expressed to allow better analysis of the data. Verbatim was not considered necessary for transcripts for two reasons: firstly, transcribing verbatim involves the transcriber and the reader having to place a large degree of interpretation on the inflections, which can change the understanding of the data and affect the results; and secondly, extensive field notes have been found to be superior to audio recordings transcribed verbatim (Halcomb & Davidson 2006). Such field notes were taken during each interview and repeated words or particularly emotive points were flagged in these notes. This gave quick ease of reference when analysing interview data. Transcripts were then read and manually highlighted as a preliminary analysis. The transcripts were then uploaded to NVivo, a qualitative research software program, and were then coded and sorted by the Research Team. The codes were emergent, coming from the research, rather than having been pre-written, which allowed for the data to determine the key themes rather than trying to fit the data to preconceived themes (Jansen 2010). The coding used was similar to that of the document analysis, with beliefs identified according to their proximity to the core of the coalition's beliefs structure and their relative position to the status quo. However, they could not be assessed over time but rather as a representation of that moment.

In analysing the data collected from interviews with stakeholders, patients and family, the aim was to determine which coalition each interviewee might belong to and whether the policy objectives, DC beliefs and strategies were consistent within the coalitions.

Determining which coalition each person might belong to was done through a mix of self-identification, beliefs and actions.

Interviews were analysed to determine if people considered themselves to 'belong' to a particular side of the policy debate. If this was provided then their subsequent statements about what they wanted to achieve or see in the policy debate, as well as their beliefs, were compared to others from the same coalition to determine consistency. A lack of consistency would indicate they were either not of the same coalition or that the expressed belief was a secondary belief and more open to change. Likewise, it was noted if any person indicated

that they had a perceived opponent, or viewed a person engaged in the subsystem with a 'devil shift' mentality, whereby by one coalition will over-emphasise the negative underpinnings of their opposing coalition's behaviour, motives and actions (Sabatier, Hunter & McLaughlin 1987). Perceptions of opponents would act as an indication of belonging to the opposing coalition.

Any expression of a belief, value or objective was noted and analysed to determine if it might constitute an immovable DC belief about normative axioms, a policy belief about the particular policy subsystem or a secondary belief that revolved around the technical means of achieving the policy goals (See Appendix 2). Repetition of certain beliefs or values was seen as an indication of the depth with which the belief was held.

Action was another indication of coalition membership. Interviews were analysed to determine if participants had instigated, promoted or participated in any action towards achieving a particular policy outcome. Such actions might have included starting a petition, attending a public forum, writing to newspapers or elected representatives, or lobbying government. These actions would indicate the policy objectives of the interviewee as well as their DC beliefs.

Finally, it was noted if any interviewee recalled any particular events that were significant within the policy debate and the manner in which they recalled these. Viewing outcomes as wins, losses, positives or negatives was another indication of coalition membership.

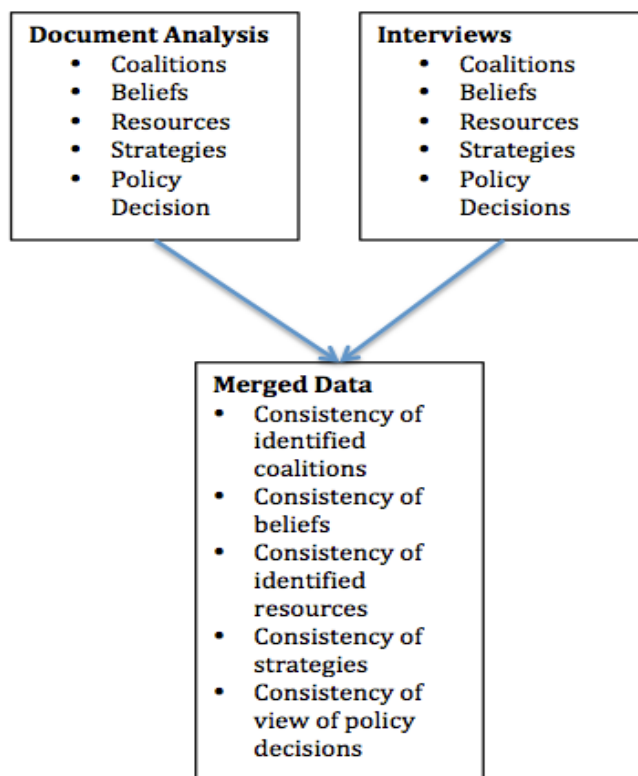
## Merging Data

Document analysis was conducted and coded to determine the active coalitions in the radiation therapy services debate, their belief systems, their strategies and their likely impact on policy decisions. Likewise, interviews conducted with stakeholders and patients/family were similarly coded according to their fit within an active coalition, their statements that reinforced a belief system, their identified strategies for influencing policy and their perceptions of the policy decisions that were made. Once complete, both were merged to identify the consistency between what was determined to be the coalitions and their actions in the document analysis and that which was identified during the interviews (see Table 11). Inconsistencies between the results of the document analysis and the results



of the interviews were flagged and noted for discussion to ensure these were acknowledged and examined for possible explanations or further research. This included discrepancies between what may have been stated publicly in government documents or media articles and what was disclosed during stakeholder interviews. Inconsistencies within interviewee's own transcripts (contradictions or conflicts) were also flagged and a section was created with this data analysis to discuss these and consider their impact on the results.

**Table 11 Flowchart for merging of two data sources**



## Researcher Effects

The researcher is the instrument for analysis across all phases of a qualitative research project...This subjective endeavour entails the inevitable transmission of assumptions, values, interests, emotions and theories...These preconceptions influence how data are gathered, interpreted, and presented. (Tufford & Newman 2012, 81)

Data collection by one person has the potential to be skewed by the views and experiences of that person, both in their effects as the interviewer and later, by the interpretation of

data. This research is certainly no different. Perceptions can be skewed by prior personal and professional experiences, individual beliefs and assumptions of what participants believe the interviewer expects of them. To situate myself in the context of this research, my own personal and professional experiences and beliefs must be examined and the strengths and weaknesses these bring made explicit and be acknowledged.

## Personal Experiences

I, as the Doctoral candidate undertaking this research (and I will refer to myself in the first person in the following sections that relate directly to my own experiences and thoughts), have been indirectly affected by cancer diagnoses of members of my family of origin, although these did not occur in the state of Tasmania. I was a resident of the North West region of Tasmania at the time of this research but did not access any cancer-related services in the region. Members of my immediate family have been affected by a cancer diagnosis of their spouse and parent within the North West region and that person, who was not known to me, did access those services. Members of my immediate family impacted by this diagnosis have made comments to me in the past about their frustrations with accessing cancer services, not just radiation therapy, in the region, as well as informally sharing their experiences and recollections with me. These accounts made me initially sceptical that the population in the North West were receiving adequate access to cancer services and that the service delivery might be fragmented, resulting in frustration for patients and family.

## Professional Experiences

From a political perspective, I have worked for political parties, politicians and Ministers from a variety of political persuasions. My previous roles have drawn me directly into political campaigning, including as a Campaign Manager for the Tasmanian Greens in the 2010 federal election, an election that is discussed often in this research. However, health services, and specifically cancer services, did not feature heavily during this campaign and my role was largely centred in the South and North of the state, not the North West. Therefore I had no contact with any person involved with the debate over radiation therapy services in the North West. It is certainly possible, however, that my political involvements

have altered my perceptions of policy decisions and political campaigning and can, in turn, introduce bias.

## Individual Beliefs

I commenced the interviews with a number of assumptions about what I thought various interviewees might believe and the coalitions they might belong to. Firstly, my assumption was that patients and family would belong to a coalition that wanted more localised services, especially radiotherapy. I assumed that this belief would be premised on the notion that patients are negatively affected by travelling to treatment, as discussed in Chapter 2, and that travel was a primary issue for them.

I also assumed that stakeholders from government departments or bodies would favour centralisation of services, as this has been the ongoing endeavour of successive governments. Likewise, it was my assumption that elected representatives were going to express the desire to meet the expectations of their electorate, and that this would make them either supportive of more localised services or appearing more as a policy broker who would facilitate and lobby for change where appropriate.

A final assumption was that the main coalition opposed to more localised services would be found in the Australian Medical Association (Tasmanian Branch). This was based on media releases issued by the AMA during the lead up to the funding commitment for the North West Regional Cancer Centre and that this view would not have changed since the Centre's opening. The only other likely members of this coalition were assumed to be those delivering radiation therapy services in other regions and those advocating for more centralisation of health services from within the government.

My personal views on local service delivery versus centralisation (and therefore more patient travel) have tended to lean towards the notion of centralisation, where appropriate. I am aware of the small population size of Tasmania and ongoing difficulties with recruiting and retaining specialised medical staff. The ongoing attempts to realign and redesign services to best fit with the human resource, economic and geographic realities of Tasmania seem sensible to me. In regard to the construction of the North West Regional Cancer Centre, I was initially unconvinced that it could be staffed in a sustainable manner, like many

services in the North West, and am yet to see what the impact will be on the delivery of services in the North, where North West residents have largely gone prior to the Centre's opening.

### Mitigating Researcher Effects

I acknowledge that simply by stating these viewpoints and experiences my bias would not suddenly diminish or disappear. Instead, it has acted as a form of self-awareness and my aim was to ensure that this awareness was used in all analysis and discussion of the data and its interpretation. Indeed, self-awareness is achieved through a process of 'bracketing', where the possible effects of preconceptions can be mitigated through in-depth reflection. It can even enhance the research as reflection promotes greater acuity (Tufford & Newman 2012).

I attempted to manage any potential bias, or impact stemming from my experiences, in my role as a researcher through a number of measures. Firstly, interviewing stakeholders in their own workplace and patients and family in their own homes was assumed to give them a stronger sense of familiarity and therefore security and confidence. Using a semi-structured interview format, where I attempted to make no declarations of any personal views, opinions or past political involvements, was also assumed to mitigate bias. I attempted to place no significance on any aspect of the research and indicated no predetermined directions or conclusions. The minimal use of formal questions were used on the assumption that this meant participants were able to discuss their own views freely with minimal possibility of my views 'steering' the conversations. Equally, each participant would have had different assumptions of what they may have thought I wanted to hear, if they had these thoughts at all, and therefore it is assumed that any bias would not have been systematic. Also, it was assumed that the rapport built by face-to-face contact would allow the participant to become engaged in the uncensored process of relaying their story, which may have led them away from any preconceived notions of what they ought to say (Irvine, Drew & Sainsbury 2013). By not disclosing my political involvements I attempted to avoid altering the response of the participants, who might have changed their approach based on their own political leanings. Finally, audio recoding of interviews was seen to mitigate bias as these could be played and reviewed by all members of the Research Team and any bias in the interpretation of what was said could be identified and addressed.

A final impact on participant's responses may have been their perception of the nature of my research, particularly interviews with stakeholders. It is possible that people working within radiation therapy services may have thought part of the aim of my research would have been to point out flaws in the services they deliver and to provide criticism of the current system. This could have created a sense of defensiveness or hostility among stakeholders, thereby altering their responses.

These concerns were mitigated by clearly outlining the aim of the research and stressing the theoretical nature of the analysis. By emphasising that the issue of radiation therapy services was to be analysed to see how it fit with the elements and hypotheses of the ACF, the focus was taken away from the perception of determining what was 'right' or 'wrong' about current service delivery.

Overall, researcher effects were mitigated by overarching supervision by a team of three experts in the fields of health and policy. All aspects of the research undertaken were assessed and critiqued by these three supervisors and clarification and expansion was suggested in areas to ensure bias or assumption was removed or minimised. The input of these three supervisors ensured that all evidence was approached with an open mind of the likely outcomes and that preconceived ideas were challenged.

## Summary

This chapter provided a thorough discussion of the methods used to design and undertake data collection in order to examine the research aims and provide academic rigour. The procedures for study design, data collection and data analysis for both documents and interviews were outlined, as well as discussion of the process for sampling and recruitment during the interview phase of data collection, highlighting that the quality of the research was underpinned by credibility, reliability and validity. Reference to the NHMRC principles for human research, and discussion of the specific efforts undertaken to adhere to these principles, ensured ethical considerations had been met. By providing clarity around research design and data collection, as well as discussion of any limitations to this, replication of the search process is ensured and the results gathered through two separate

data collection procedures represent as complete a picture of the research focus as is possible. The results are discussed in two separate chapters, one for each data source.

# Chapter 4: Results I – Document Analysis

## Introduction

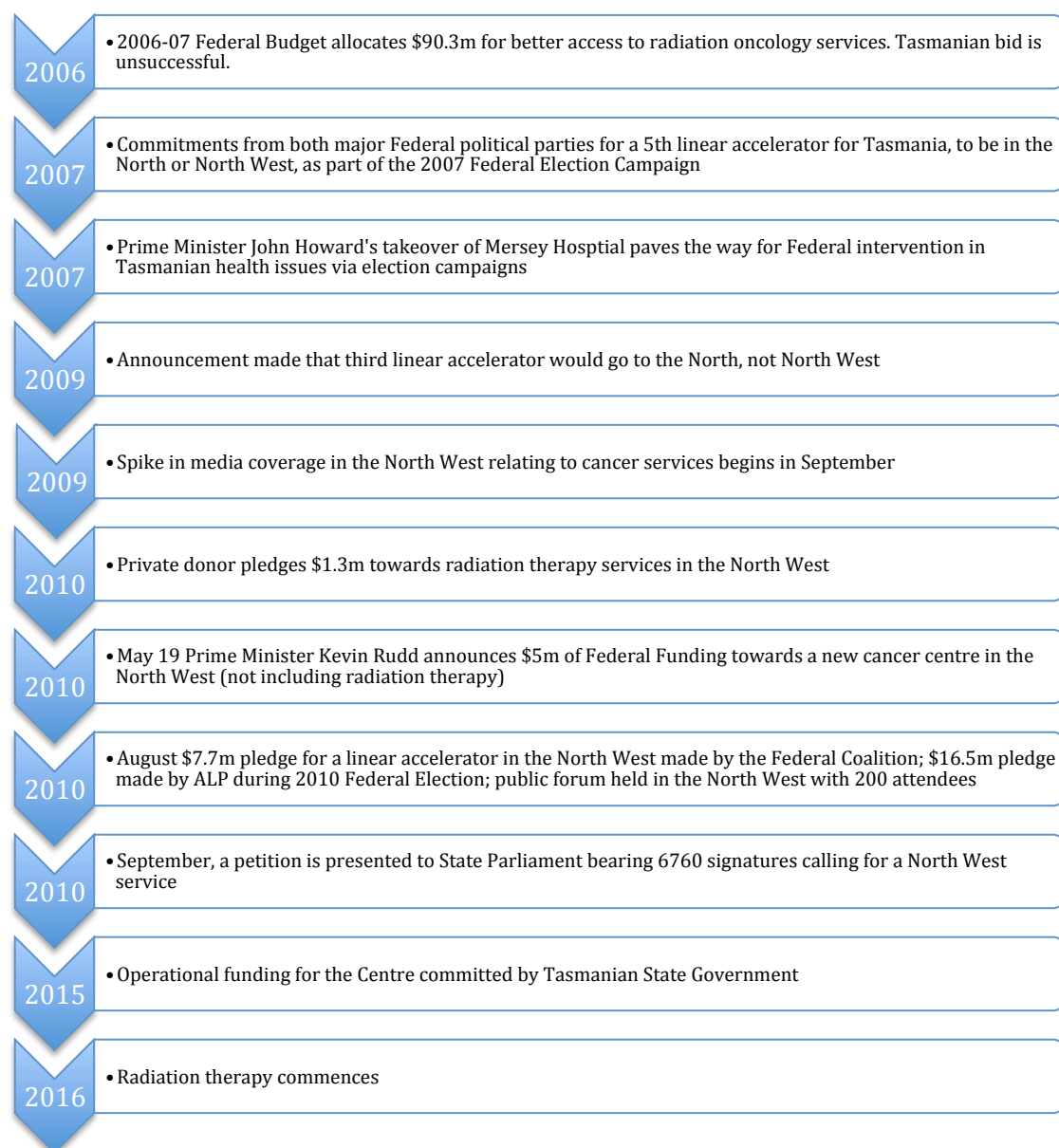
This chapter presents an analysis of publicly available documents in relation to the design and delivery of radiation therapy services in Tasmania and particularly North West Tasmania (see Appendix 6 for a full list of documents). A discussion of the ACF flowchart is also presented early on with reference to Tasmania and its cancer service system in order to provide context to the analysis using the ACF. The documents discussed in the Beliefs section of this chapter were analysed to examine the exact nature and composition of the policy subsystem. It explored the beliefs of key actors in the policy subsystem across four periods of time relevant to the policy debate and ascribes a level to these values. These were used to determine the possible composition of the coalitions involved. This chapter provides ongoing evidence to test the hypothesis that the debate around extending cancer services in North West Tasmania during the period 2000-2017 was born out of politically motivated change rather than the actions of a formally organised coalition.

## Cancer Services in North West Tasmania: the Advocacy Coalition Framework Flowchart

To give context to the analysis of documents relating to radiation therapy services in North West Tasmania and the establishment of the North West Regional Cancer Centre, a brief chronology of key events was compiled to highlight the key events that earmarked the policy debate and the development of the issue among key actor groups (see Table 12). It begins with a commitment in 2006 by the federal government to fund better access to radiation therapy through a \$90.3 million scheme, where Tasmania was unsuccessful in its bid (Contract Review Committee n.d.). Then came the funding commitment for a third linear accelerator for the Northern region of Tasmania, which resulted in increasing media coverage on the issue of North West access to radiation therapy. In 2010 multiple funding commitments were made for the North West, firstly for a new cancer centre that would

have a bunker but no immediate radiation therapy, and then for full radiation therapy services. From this came the construction of the NWRCC, which opened in late 2015.

**Table 12 Chronology of events relating to North West radiation therapy**



The chapter proceeds with a systematic analysis of documents according to the elements of the ACF Flowchart (see below). This analysis enabled the flowchart to be populated with evidence specifically linked to the cancer services debate in North West Tasmania and for the policy subsystem to be established. Once the parameters, events, resources, opportunities and constraints are established an analysis of four periods of time relevant to the policy subsystem allows for the major actors to be identified.



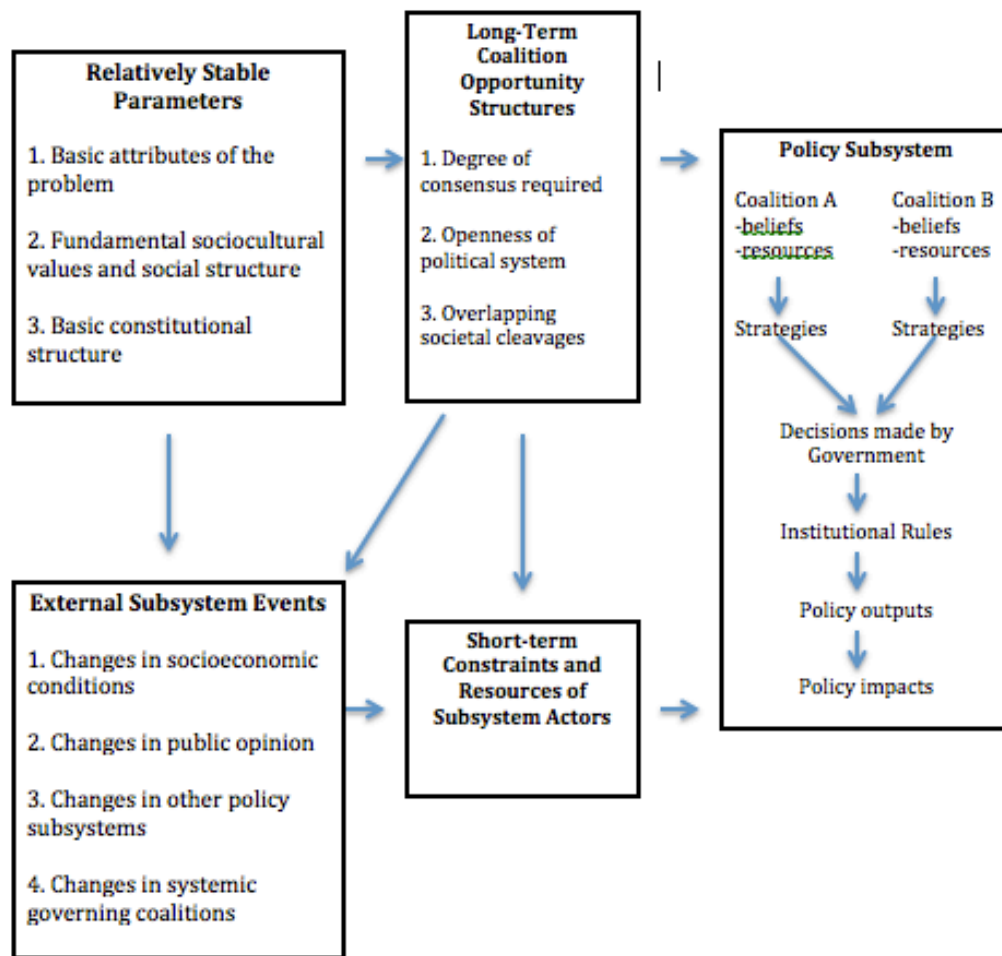


Figure 11 Advocacy Coalition Framework flowchart

## Relatively Stable Parameters

### *Basic immutable attributes of the problem*

First, there has been and continues to be a high incidence of cancer in Tasmania, which also has the second highest mortality rate from cancer in Australia (North West Radiotherapy Clinical Expert Panel 2011). This mortality rate is further compounded by the increased lifestyle and risk factors that are linked to socioeconomic determinants of health and the higher prevalence of such risk factors among the North West population. For example, in 2009 the Tasmanian rates of daily smoking, excessive alcohol consumption, insufficient physical activity and inadequate vegetable consumption were all higher in the North West than the rest of the state (Tasmanian Health Organisation - North West 2013). This was particularly notable for smoking, with 17.4% of the North West population being daily smokers, compared to 16.2% Tasmania-wide. This has been identified as a health priority by

the Tasmanian government, with a focus on tobacco control measures and liquor licensing legislation promoted as a mechanism to control such lifestyle risk factors (Department of Health and Human Services 2013a). This could, in part, explain why 28% incidence of oesophageal cancer in Tasmania occurred in the North West in 2012, when the region's population was only 23% (Stokes et al. 2015).

Another consideration is the correlation between living in a rural or remote area and poorer health outcomes, which are in part linked to socioeconomic and cultural conditions (Department of Health and Human Services 2013a). The North West towns of Burnie and Devonport are classified as Outer Regional (RA3), and service Remote and Very Remote areas, including the West Coast and Kind Island (Department of Health 2016). While the incidence for all cancers is lowest in very remote areas (398 per 100,000), the mortality rates are highest in remote and very remote areas (192 per 100,000) (Australian Institute of Health and Welfare 2014b), meaning that while less cancers were diagnosed in these very remote areas, more people were dying from them. Overall, patients from regional and remote areas have a 7% higher mortality rate than their metropolitan counterparts, based on cancer type (Fox & Boyce 2014). Discrepancies in cancer outcomes for people in regional and remote areas do not relate solely to mortality. They also relate to the likelihood of surgical intervention and reconstruction, access to radiation therapy, follow-up by specialists, delays, the burden of travel, and continuity of care (Council of Australian Governments Reform Council 2013; DLA Phillips Fox 2010; Heathcote & Armstrong 2007; Senate Community Affairs References Committee 2005).

Health care itself continues to be expensive and is becoming more so. Australia's healthcare spending relative to GDP has risen from 7.4% in 1999-2000 to 9.4% a decade later and continues to surpass the rise in all other goods and services (Australian Institute of Health and Welfare 2012a). This creates a situation for states such as Tasmania around capacity to meet demand, with estimates pointing to Tasmania's health costs consuming its total budget by 2022 (Eccleston 2013).

### *Distribution of natural resources*

Tasmania is the smallest state both geographically and in population size, which constrains its capacity to generate sufficient economic activity and thereby provide services. This is further impacted by its island status, creating an additional layer of cost to the movement of people and goods between Tasmania and the mainland (Brindley & Turner 2015).

Tasmania's North West regional capitals, Burnie and Devonport, are growing at a slower rate than other regions of Tasmania and Australia, ageing at a faster rate and rank as two of the most socioeconomically disadvantaged areas in Australia (Brindley & Turner 2015). This increases the cost of delivering health services because of the link between socioeconomic status and health outcomes (Duckett et al. 2002). Tasmania remains below average in key economic drivers while the North West is largely dependent on mining and primary production for economic growth but industries in this sector are heavily affected by changes in commodity prices (Brindley & Turner 2015).

The small and dispersed nature of the population results in low volume of service activity outside of the major centres of Hobart and Launceston, creating 'diseconomies of scale' and preventing the comprehensive provision of health services statewide (Commission on Delivery of Health Services in Tasmania 2012b, 15). With a population of a little over 91,000, the North West has been considered too small to create the critical mass required to have standalone radiotherapy services and attract staff (Bingham 2015d; Duckett et al. 2002). A viable radiotherapy unit was instead considered in areas of 200,000-250,000 residents and 1000+ new cancer cases per year (Dunlevy & Crawley 2014). However, the Clinical Expert Panel assembled to consider the best option for delivering services in the North West did find that there was sufficient throughput in the region to support a radiation therapy service (North West Radiotherapy Clinical Expert Panel 2011). The Panel did, however, advise against a standalone service citing difficulties associated with the recruitment and retention of specialist staff and lack of critical mass of patients.

### *Sociocultural values and social structure*

The provision of cancer services, like all health services, are seen as the responsibility of the government of the day (Townsend cited in Shannon 2009) and the extent of such services will

reflect the value society places on them. This value is shaped, in part, by the dominant voices in the health debate. Palmer and Short (2014) believe the medical profession holds an unrivalled position of power in influencing health service design and policy, as well as determining numbers of specialist training places. This comes as a consequence of its male-dominated ranks and its prestige drawn from the historically high socioeconomic background of medical professionals. This dominance is despite the fact that medical professions make up only 17% of registered health care professionals, while nurses, who make up the majority of the health workforce at 63%, have considerably less influence (Australian Institute of Health and Welfare 2012a).

However this dominance has been challenged by the rise of the consumer health movement (Shannon 2009) and the increased involvement of the patient in controlling their treatment and management (Cushen, South & Kruppa 2004). The Consumers Health Forum of Australia conducted a study of consumer interests and expectations (Consumers Health Forum of Australia 2011). This survey found that patients want easy access to reliable information from both health professionals and from other consumers, so that they can more proactively participate in their own health. This fits well with the ideals of the State of Public Health Report (Department of Health and Human Services 2013a), which advocated greater consumer awareness and involvement as a key to resolving the underlying causes of poor health outcomes in Tasmania. Patients also indicated in the survey that they want more involvement in policy discussions and decision-making through consumer-focused representation (Consumers Health Forum of Australia 2011).

This expectation of involvement by patients, in addition to a universal free health care system, creates a culture of increased consumer demand for the maximum possible range and accessibility of services. This is reflected in the introduction of radiation therapy services in North West Tasmania. Political support for expanded cancer services in 2010 prompted the Australian Medical Association Tasmania (AMA) to publicly state that any expansion should not include a linear accelerator (Australian Medical Association Tasmania 2010c). The chief concerns of the AMA were in relation to the recruitment and retention of the specialised oncology staff required to operate a linear accelerator, as well as the lack of precedent for operating a single-unit facility with a population of 100,000. However, the view of government was at odds with the AMA, resulting in the funding commitment being

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made. This was seen as a response to the petition and subsequent public forum, which were indicative of a consumer health movement at odds with the established power brokers.

Social structure is described in terms of parameters, the core values of the society, within which actors must operate 'in order to remain relevant to routine political realities' (Girvin 1993, 388). In Tasmanian society, the social structure reflects one of a secular state that has family at its core (Adams 2009). Therefore society will perceive policy debates through the lens of family and consider how any policy change might affect the capacity of the family to be together and build resilience (Adams 2009). In the policy debate on cancer services this family focus manifested in the form of statements from media and elected representatives alike about appropriate travel distances and removal from support structures (ABC News 2010a; Clark 2010; Department of Health and Human Services 2010, 2014a; Tasmania 2010a). The repeated framing of the policy debate through the lens of family and separation from family support networks created parameters within which policy actors had to operate in order to be recognised as fitting the social structure and those that did not appropriately recognise these were not as easily recognised in the policy debate.

### *Basic constitutional structures*

Tasmania is heavily reliant on Commonwealth funding, having the second lowest capacity to raise the revenue required to provide health and other services in Australia (Commonwealth Grants Commission 2014). Tasmania also remains heavily reliant on the current GST distribution, receiving approximately 1.5 times its population share of GST revenue because of its limitations on raising revenue (Tasmanian Government 2011). This creates the opportunity for Commonwealth funding to be used to bolster or indeed override the health direction of the state government. Through a complex network of direct and tied funding to both states and private providers, as well as rebates to consumers, the Commonwealth funds health services, some of which it is also responsible for delivering, such as aged care and primary care, while leaving responsibility for the acute sector to states (Australian Government 2014). Therefore, the provision of cancer services in Tasmania is a state government responsibility and the Constitution does not recognise a role for the federal government in this. However, it is a long-standing reality that the federal government can and does use funding arrangements to effect change in the areas of health controlled by

states, particularly through the Australian Health Care Agreement (AHCA) and National Healthcare Special Purpose Payments (SPP). The AHCA commenced in 2003 as a grant to assist states in providing hospital services. While the AHCA is not tied to specific projects, the funds are tied to strict performance targets which are based on programs proposed by the federal government (Dalton 2006). The AHCA was retired in 2009, leaving SPP as the remaining source of project-specific funding (Australian Institute of Health and Welfare 2013a). This draws a direct line of accountability between state health services and the federal government and creates an opportunity for influence at the federal level.

The Issues Paper on Health, as part of the White Paper on the Reform of the Federation, sees the current division of roles and responsibilities between states and the Commonwealth as problematic, leading to cost-shifting and blame-shifting between providers, confused lines of accountability, duplication of some services, poor workforce planning, a lack of flexibility and innovation, and ineffective policy (2014).

The Hare Clark system of voting used in Tasmanian state elections is a distinct component of Tasmania's political environment. In the Hare Clark system five-seat electorates are filled using a highly preferential voting system, which results in candidates competing not only with those of other parties but those from within their own party (Shannon 2009). This can lead to candidates being more responsive to issues of importance to local communities, which can include the community's sense of isolation from services in major centres and a sense of protection for the level of services within the local community. Additionally, the North West federal electorate of Braddon remains a marginal seat, a fact that has led federal candidates to respond more directly to the perceived wishes of the regional community. This includes the federal takeover of the Mersey Community Hospital, on the outskirts of Devonport, during the 2007 federal election campaign – move widely regarded as an exercise in pork-barrelling (Grube 2010; McCall 2010).

## External Subsystem Events

### *Changes in socioeconomic conditions*

The small size of Tasmania means the state is particularly vulnerable to changes in socioeconomic conditions and therefore external events can perhaps have stronger

ramifications for Tasmania than for other states. Falling commodity prices have affected not just the mining industry as a cornerstone of the North West's employment but the manufacture of mining equipment, leading to the loss of jobs in major employers such as Caterpillar (Brindley & Turner 2015). Equally, the falling commodity price has created stronger pressure from mining states, such as Western Australia, to re-examine the distribution of the GST (Tasmanian Government 2011). In Tasmania, health sector design is further impacted by ongoing budgetary constraints as a lingering effect of the Global Financial Crisis (Ogilvie 2012), a decrease in the average number of hours worked by many health professionals, and an increasing reliance on overseas trained health workers (Australian Institute of Health and Welfare 2012a).

### *Public opinion*

Sentiment favourable towards extending cancer services in North West Tasmania began to find traction during the 2000's. There was an absence of any notable discussion among the community (via the media) on the desire for a local radiation therapy service up until 2007. Instead, there was a more general discussion on coordination of care and accessibility of services by rural patients through such forums as Senate inquiries, federal government initiatives and the state government's Cancer Framework. The Clinical Services Plan in 2007 did mention that there was sufficient demand for a single machine unit in the North West and recommended an analysis of its feasibility (Department of Health and Human Services 2007). This focus increased until there was sufficient impetus for an election commitment for another linear accelerator in the Northern half of the state in the 2007 federal election campaign (Australia 2010). This ultimately ended up in the Northern region, not the North West, because of the additional investment that would be required to build a radiotherapy service from scratch. This decision acted as a catalyst for public opinion to build further behind a North West-based service, culminating in a petition to Parliament, bearing 6,760 signatures, and a public forum with 200 attendees, on the issue on the eve of the 2010 federal election (Tasmania 2010a). Politicians and candidates alike attended the forum, resulting in funding commitments from both major parties in a swing seat.

### *Changes in systemic governing coalitions*

Changes in governments have impacted the debate on cancer services in multiple instances through both state and federal elections. Federally, governments have changed in 2007 (Coalition to ALP) and 2013 (ALP to Coalition). The state government changed in 2014 (ALP to Liberal). As a marginal seat, Braddon has been a hotbed of political activity in each campaign and it was this activity in the lead up to each election that had the greatest impact. Although a state responsibility, federal funding for extended health services are a popular tactic because of the capacity to grant Special Purpose Payments, in particular the election commitment of \$16.5 million in addition to the initial funding of \$18.7 million under the Health and Hospitals Fund (Department of Health 2013). This was a turning point in the delivery of cancer services in North West Tasmania as the funding commitment was sufficient for a purpose built oncology centre, inclusive of radiation therapy. This did not involve a change in the government but rather an attempt to retain government, an attempt that was ultimately successful. However, it was a change in the federal governing coalition in 2007 to Labor that brought about the Health and Hospitals Fund that led to the federal funding of the North West Regional Cancer Centre.

### *Changes in other policy subsystems*

The Tasmanian government has readily identified the link between health and other subsystems. In its 2013 *State of Public Health Report* the need for 'policy and regulatory engagement by non-health sectors' was considered as an important part to addressing many of the social determinants of health that create many of the modifiable risk factors relevant to some cancer types (Department of Health and Human Services 2013a, 4). This was considered a 'healthy public policy' approach, in that policies across all areas of government should be developed with improving health and health equity as a core component.

Information technology was another subsystem with potential impact on radiation therapy services. The use of e-health, including telehealth, was identified by the National Health and Hospital Reform Commission as a key initiative in transforming and enhancing health services and could potentially offer improvements in the way cancer services may be accessed (Australian Institute of Health and Welfare 2012a). Programs such as the National



Broadband Network and personally controlled electronic health records could enable e-health and positively impact on the subsystem, such as enabling video-conferenced specialist appointments for regional patients or better accessibility of full medical records by health professionals (Australian Institute of Health and Welfare 2012a).

On the reverse side, economic constraints brought about by the Global Financial Crisis have placed pressure on Treasury. Health budget cuts announced by the Tasmanian government totalled \$500 million over the four-year period 2011-15 and resulted in loss of services and staff (Australian Nursing Federation (Tasmania Branch) 2011). As of May 2015, \$2.1 billion is to be cut from health and education budgets over the next ten years nationwide (Smiley 2015b).

### Long-term Coalition Opportunity Structures

Tasmania demonstrates several key long-term structural attributes that can be conducive to facilitating change, such as cultural homogeneity, consensus and an open political system, but the mixed responsibilities in health care funding and delivery can create a challenge.

#### *Overlapping societal cleavages*

‘Overlapping societal cleavages’ refer to the accumulated impact of social, economic, ethnic, religious divides within society. The greater the overlap, the higher the risk of conflict and the stronger the likelihood of a corporatist policy style being dominant. (Shannon 2009).

Tasmania has lower than national average levels of ethnic and religious diversity (Department of Immigration and Border Protection 2014), which can lead to more social cohesion. For example, in the 2011 Census it was identified that the number of people born overseas was 24.6% nationally but only 11.6% in Tasmania. Of those born overseas, fewer than half came from non-English speaking nations. There is also limited political diversity, with only two parties holding party status in the Tasmanian Parliament (after the 2014 state election) and only seven registered political parties contesting the most recent state election (2014), with only three parties winning seats (McCann 2014). This creates a society that is largely of the same cultural background, which in turn creates less difference in societal expectation.

### *Degree of consensus required*

At times during the cancer services debate there has been a high degree of consensus between key stakeholders. For example, during the 2010 election campaign there were Labor governments in office both federally and in Tasmania, as well as a Labor member in the federal electorate of Braddon. This enabled the Braddon incumbent to leverage federal funding to achieve a cancer service commitment that would otherwise have been a state responsibility. Community consensus had been gauged through the forum held prior to the election and the monopoly over governments by the ALP meant the federal and state governments could work in lockstep to deliver a key election issue. However, the powerful Australian Medical Association (Tasmanian Branch) was sceptical of the capacity to host a radiotherapy service in the North West and was one of the few notable dissenting voices to the plan (Australian Medical Association Tasmania 2010c). This was in contrast to previously high levels of consensus between the AMA and policy makers on issues such as health reform (Shannon 2010).

### *Openness of political system*

In terms of the Tasmanian health system this would involve both Houses of Parliament as well as the likely inclusion of the federal government (and both federal Houses of Parliament if required) as the key funding source for new initiatives or expansions. The political system is a largely open and democratic one, with individuals able to petition the government directly, as was the case of the petition presented to the Tasmanian Parliament calling for a North West radiotherapy service (Tasmania 2010b). Stakeholders are also free to exert influence through the election process in both state and federal elections by lobbying parties and candidates as well as garnering public support. This is in contrast to corporatist systems that restrict such direct participation (Weible, Sabatier & McQueen 2009).

### *Short-term Constraints and Resources of Subsystem Actors*

The original flow chart for the ACF does not list any specific subcategories under 'short-term constraints and resources of subsystem actors'. However, six categories of resources are identified and can be considered in this context – formal legal authority to make policy

decisions; public opinion; information; mobilizing of troops; financial resources; and skilful leadership (Weible et al. 2011).

Elections are a key opportunity to harness public opinion and mobilise latent actors to effect policy change. Latent actors are described by Sabatier (1988), as those who will only enter a policy debate when they have information necessary to motivate them but are otherwise disengaged for active participation in the policy subsystem. They form a reliable and predictable window of opportunity to move an issue onto the political agenda (Howlett 1998). Consumer representatives and candidates harnessed such a window in the 2010 election, when a community forum followed a region-wide petition calling for a North West radiotherapy service and parties both sought to commit funding to the project. The community forum was able to take members of the public who might otherwise have only held an interest in cancer services and turn them into active participants in the policy discussion, something which consumer groups are often unable to sustain outside of peak periods of activity (Shannon 2009).

Reports and expert knowledge, as a form of information, are also routinely used to propose or oppose policy change. For example, the Tasmanian government was able to delay the commencement of the North West Regional Cancer Centre until an expert panel had provided advice on its feasibility and design, a move that met with outrage from the opposition (Tasmania 2010a). The Report was then able to be used as a resource upon which to base the design of the service – as an extension of the Northern Integrated Cancer Service rather than as a standalone service (North West Radiotherapy Clinical Expert Panel 2011). The credibility of the Expert Panel and the formal legal authority of the state government to make the final decision on the design of the service both worked in the favour of the then-Labor state government. Similar expert opinion is being used in the One Health System White Paper to garner community support for a structural overhaul of the Tasmanian Health System based on cost, sustainability and maximising resources (Department of Health and Human Services 2015b).

A critical constraint on increased local cancer services is the ongoing issue of recruitment and retention of specialist staff, not just within the region, but statewide. The Clinical Expert Advisory Panel's report highlighted the need for adequate levels of staffing to safely

maintain a radiotherapy service, including the need for staff that live full-time in the vicinity (2011). Cancer services pre-2016 relied heavily on a small number of specialists and little support staff. This means many services have relied on the precarious availability of a single practitioner and changes to their availability can have a significant impact on patients (DLA Phillips Fox 2010). This was exemplified when a Hobart-based oncologist, who provided an outreach service to the North West, resigned in 2009, leaving the North West with no coverage while alternatives were found (Bingham 2009a).

When the North West Regional Cancer Centre was given final funding approval, the AMA Tas was quick to state that it did not believe the region could adequately staff a radiotherapy service because of the statewide, and indeed even nationwide, shortage of medical oncologists and other specialists (Dolan 2011). The North West has had a long history of being unable to recruit and retain specialists and relies on many visiting specialists. Indeed, medical oncology operated for three years on the North West Coast with a specialist flying in from Melbourne's Peter MacCallum Cancer Centre three days a week. Despite patients, doctors and bureaucrats alike praising the efforts and success of this arrangement, the Liberal state government recently referred to it as a 'failed model' (Department of Health and Human Services 2015a).

One solution originally discussed was to rotate staff between the North and the North West sites, in addition to continuing to use the Melbourne-based oncologists – a far cry from the original objective of having specialists living in the vicinity full-time but reported as a reality because of the lack of critical mass in the region to attract the required clinicians (Bingham 2014b). Staffing and recruitment issues seem to have been nullified, however, with 42 applications for four Radiation Therapist positions at the new Centre (Bingham 2015g). However, the question of retention of these new staff members remains.

## Policy Subsystem: Beliefs and Coalitions

With the elements of the ACF flowchart populated using documents relating to the issue of cancer services in North West Tasmania, the context for the policy debate has been established. This enables analysis of those documents that helped to understand the policy subsystem that was created, which is the collection of actors involved in debate about this

policy issue. This included a set of 130 documents derived from the two initial searches conducted for the Literature Review and an additional manual search, as discussed in the Methodology Chapter, 99 of which were included in the document analysis. This analysis was presented by breaking the analysis into actors, beliefs and time periods.

Document analysis focused on the stated viewpoints, beliefs and actions of these major actors, in order to establish consistency of beliefs over time and consistency of beliefs between actors, which may then constitute a formal coalition. These were ascribed a value – Deep Core (DC), Policy Core (PC), and Secondary Aspects (SA) (See Appendix 2) – based on the classifications outlined in Sabatier (1988). In these two documents beliefs are given defining characteristics, scope, susceptibility to change and illustrations. For example, deep core beliefs are those that form part of a basic personal philosophy and would apply to any subsystem, not just radiation therapy services, such as the concept of equality. Policy core beliefs apply only to the policy subsystem and would not necessarily be assumed to apply to other areas, such as the belief that coordination of care in cancer services is fragmented. Secondary aspects are specific to the subsystem and include such aspects as budget, resources, administration and the scale of the problem, which relates to beliefs pertaining to recruitment and health budgets. Key beliefs were determined based on whether something was stated as a fact or an opinion, whether there was repetition and therefore salience of certain words or concepts, and whether identifiers, such as ‘I believe’ or ‘I think’ were used. The coding included both the beliefs of the document’s author and what they perceived to be the beliefs of others. This coding of beliefs was developed using thematic analysis as described by Braun and Clarke (Braun & Clarke 2006). Documents were read and re-read and themes were derived. Repeated words, phrases or concepts, such as ‘coordination of care’, or concepts with clear importance, such as patient safety, were noted, coded and then compared to other documents for thematic development. The list of beliefs and ascribed values are found in Table 13.

**Table 13 Key beliefs and ascribed level of value**

Belief	Level
Coordination of care	PC
Support	SA
Travel & Transport	PC
Safety and sustainability	DC
Centralisation versus maintenance of services	SA
Multidisciplinary Care (MDC)	SA
Equity & access	DC
Politically-driven change	PC
Staff skills	SA
Duplication of services	SA
Recruitment & retention of staff	SA
Health budgets	SA
Community expectations	PC
Urgency of the issue	PC

Note: DC – Deep Core, PC – Policy Core, SA – Secondary Aspects

The major actors identified from the document analysis were:

#### ***Federal Health Policy Actors***

This group constituted all stakeholders working or operating at a federal level in the debate, design or implementation of cancer services affecting Tasmania.

#### ***State Health Policy Actors***

This group constituted all stakeholders working or operating at a state level in the debate, design or implementation of cancer services affecting Tasmania.

#### ***Health Professionals***

This group constituted those working in a health profession or as part of an organisation that represented a health profession. This includes medical professionals, nurses and allied health professionals.

### ***Community and Community Advocates***

This group consisted of members of the public or organisations or groups whose role was to advocate on behalf of the community or cancer patients.

### ***Media***

This group consisted of those employed in the media industry that provided comment relating to cancer services in Tasmania as part of their occupation, or media outlets themselves where no reporter or author was identified.

Each group was not necessarily assumed to be a coalition in its own right but rather a logical grouping of actors impacting the policy subsystem who may be part of a coalition.

## **Beliefs**

The stated viewpoints, actions and beliefs of each group were further categorised into four periods. Separation into discrete and distinct periods allows major changes in the policy subsystem to be used as markers to identify whether beliefs and actions of major players stayed consistent from that point or whether they resulted in changes to coalitions, beliefs and policy objectives.

### ***Pre-Nov 2007***

Those documents from 2000 up until the 2007 federal election, which resulted in a linear accelerator being committed to the Northern region rather than the North West, which can be seen as a possible catalyst for change in the provision of cancer services in the region

### ***Nov 2007-Aug 2010***

Those documents between the 2007 federal election, which included a commitment to fund a third linear accelerator in the Northern half of the state, and the 2010 federal election, when funding for a radiation therapy service was committed thereby providing extended cancer services in the region

### ***Aug 2010-Nov 2015***

Those documents between the 2010 federal election and when the Centre partly opened in late-2015 (the commencement of medical oncology)

### ***Nov 2015-***

Those documents after the North West Regional Cancer Centre began

*onwards* providing medical oncology (late 2015, with radiation oncology commencing in mid-2016) and the present day

In total, 99 documents were included in the analysis of beliefs (see Table 14). Some documents provided evidence of belief among more than one group, with 131 applications of the 99 documents across five groups and four periods.

**Table 14 Documents by group and time period**

Group	Pre-2007	2007-2010	2010-2015	2015 onwards
<b>Federal</b>	3	9	7	1
<b>State</b>	3	16	25	1
<b>Health Prof</b>	9	5	12	0
<b>Community</b>	6	9	9	3
<b>Media</b>	1	6	4	2
<b>n = 99 documents, 131 applications</b>				

The documents included involved 12 types, both electronic and hard copy (see Table 15). These documents varied in characteristics, length, authorship and peer review. Some documents were short Letters to the Editor, while others were full Senate Reports. Some were written by health professionals, others by journalists or members of the public. This was considered necessary in order to capture the fullest possible representation of beliefs across groups to best gauge the possible coalitions. As Letters to the Editor and media articles were often the only written form of this expression from members of the community these were included in addition to formal government and non-government reports. Without these, a less complete picture of viewpoints and beliefs would have been achieved.



**Table 15 Documents by type**

Document Type	n
Conference Paper	1
Government Report	15
Hansard – Federal	1
Hansard – Tasmania	4
Information Booklet	1
Journal Article	3
Letter to the Editor	11
Media Release	5
News article (electronic or print)	48
Non-Government Report	4
Petition	1
Submission	5

***Pre-Nov 2007***

The period from 2000 to the 2007 federal election can be seen as a time of minimal discussion of the need for extended cancer services, namely radiation therapy services, in North West Tasmania, with only some recommendations for further examination made. It was, however, a period of strong national discussion on the best ways to improve cancer service in rural and remote areas (Department of Health 2005; Senate Community Affairs References Committee 2005). The key beliefs expressed centred around coordination of care, travel, physical and psychological effects on patients, sustainability, sufficient patient throughput, maintenance of existing services in regional areas, education campaigns, multi-disciplinary care, improved facilities, health inequities, centralisation of services, political divides and support services (see Table 16).

**Table 16 Evidence of beliefs by major actors, Pre-Nov 2007 (n= total number of documents)**

<i>Belief</i>	<i>Federal (n=3)</i>	<i>State (n=3)</i>	<i>Health Prof (n=9)</i>	<i>Community (n=6)</i>	<i>Media (n=1)</i>
<b>Coordination</b>	✓		✓	✓	
<b>Support</b>	✓			✓	
<b>Travel &amp; Transport</b>			✓		✓
<b>Safety and sustainability</b>		✓	✓		
<b>Centralisation versus maintenance</b>			✓	✓	
<b>MDC</b>			✓		
<b>Equity &amp; access</b>	✓	✓	✓		
<b>Political change</b>					
<b>Staff skills</b>	✓				
<b>Duplication</b>		✓			
<b>Recruitment &amp; retention</b>		✓	✓		
<b>Health budget</b>		✓			
<b>Community expectations</b>					
<b>Urgency of the issue</b>					

### ***Federal health policy actors (n=3 documents)***

The period from 2000 to the 2007 is marked by sporadic efforts by the federal government to improve care services and coordination of these services. Cancer had become a National Health Priority Area in 1996, leading to increased focus on government responses to this issue. In 2001, the federal election resulted in a \$72.7 million commitment to improve access to radiation therapy for rural areas, which included some new centres, none of which were earmarked for Tasmania (Clinical Oncological Society of Australia 2006). In 2005 the Senate referred the matter of services and treatment options for persons with cancer to the Senate Community Affairs Reference Committee. This Committee expressed concerns over the apparent lack of coordination of some aspects of the cancer care system, including information sharing between jurisdictions.

During the course of the inquiry the Committee was advised that there were more than 100 government and non-government organisations that contribute to cancer policy or are involved in cancer treatment or support around Australia... The Committee recognises the valuable role played by these services, however, given the increasing burden that cancer will place on the community in the coming years the Committee believes that there is a need to ensure that cancer resources are well organised, used efficiently and effectively and that any potential for duplication and overlap is addressed (Senate Community Affairs References Committee 2005, 5).

In the same year, the federal government introduced the *Strengthening Cancer Care Initiative*, a \$189.4 million commitment aimed at improving coordination of care, support and mentoring, screening, research, and palliative care (Department of Health 2005). Initiatives relating to radiation therapy or to specifically extending cancer services in North West Tasmania were not discussed in either the Senate Report or the *Strengthening Cancer Care Initiative*. However, the Senate report did cite evidence that doctors who treat high caseloads of certain cancers achieve higher survival rates, indicating that sufficient throughput and maintaining skills were considered important to the Committee. This is something deemed relevant to the provision of cancer services in North West Tasmania, a regional area with limited throughput of patients for oncology-related medical professionals.

Only one example of an overt statement in relation to cancer services in North West Tasmania by a Federal Health Policy Actor (FHPA) was found, a statement made by then-Prime Minister John Howard in 2007 that it was not 'unreasonable' for residents of the North West to want access to 'the normal routine of medical services' (Ford 2007a). This comment was made in relation to a Budget commitment for an MRI unit in the North West, something that did not eventuate until private funding was obtained.

### *State health policy actors (n=3 documents)*

The same period was similarly characterised as a time of minimal discussion at a state level explicitly on the need for extending cancer services or access in North West Tasmania, with only a few exceptions. This period was marked by two major health reform plans commissioned by the state government: *The Tasmanian Hospital System: Reforms for the*

21<sup>st</sup> Century (more commonly known as the Richardson Review or the Expert Advisory Group Report) (Expert Advisory Group 2004) and the *Clinical Services Plan* (Department of Health and Human Services 2007). Both of these plans reviewed cancer services in Tasmania as part of their gamut.

The Expert Advisory Group, chaired by Professor Jeff Richardson, made two recommendations relevant to the provision of cancer services in Tasmania: firstly, that

the Tasmanian government conduct an economic evaluation of costs and benefits of an expansion of home, rural and regional treatment options for chronic disease and palliative care. (2004, 6)

Secondly, that any significant relocation of services only occur after consideration is given to transport services. This was in recognition of the finding that the Tasmanian Ambulance Service was struggling to meet the demands that follow on from specialist services. The Review found that lifestyle and social factors were the main cause of a range of chronic diseases, including cancer, and that the solution needed to focus on changing these lifestyle factors by living healthier lives. It was suggested in the Review that a shift in funding from tertiary to primary health sectors would be required to achieve this, with an emphasis on educational campaigns. The Review recognised that meeting increasing demand for cancer services would only be achieved through having an appropriate supply of staff, not only through recruitment but retention of those already in Tasmania.

The extent to which the mainland states and overseas countries are prepared to offer considerable attractions both in remuneration packages and lifestyle options cannot be ignored by the Tasmanian decision makers nor by the administration which serves them. It is clear from information provided both by hospital administrators and medical staff, that the future recruitment and retention of specialist clinical staff and supporting resident workforce will be dependent on their ability to respond rapidly and appropriately to the medical workforce market in a rational way. Successful recruitment of excellent staff in this competitive marketplace will also depend upon the reputation of Tasmania as a place of quality service delivery, matched by a

positive and productive place of endeavour for the workforce involved.

(Expert Advisory Group 2004, 41-42)

It went on to discuss the need to remove duplication of services and linked this to the need for improved safety and quality of patient care.

The Clinical Services Plan, released in May 2007, outlined both the current level of service delivery in each health service area, including cancer services, as well as addressing any changes required to these levels (Department of Health and Human Services 2007). In this, radiation oncology services were examined and it was found that 'the current distribution of services in Tasmania is appropriate, although patients from the North West remain relatively disadvantaged in terms of access to services' (Department of Health and Human Services 2007, 113). It was confirmed that the population of the North West would generate sufficient demand for a single machine service and a recommendation was made that such a regional outreach service be examined for feasibility. It was noted that these findings were consistent with the findings of another report commissioned by the Department of Health into the increasing demand for radiation therapy services in Tasmania. However, efforts to obtain a copy of this report under the *Right to Information Act 2009 (Tas)* were unsuccessful, with the report deemed an internal document. This provides evidence that the need for radiation therapy services was the subject of discussion within the state government but not discussed externally. The Clinical Services Plan stated that the Department of Health would examine the capacity to recruit the staff needed as well as a cost/benefit analysis of building a service in the North West as opposed to increasing capacity at the Launceston Holman Clinic.

The Department will undertake a careful feasibility study to assess

- the ability to recruit radiation therapists and technical support staff including physicists to a more remote service;
- the cost burden to the system of developing a single machine service compared with an additional linear accelerator at the existing Holman Clinic; and

- whether additional Commonwealth support could be attracted because of the potentially substantial benefits to the community of developing such a service

(Department of Health and Human Services 2007, 114)

No further results were found on any investigations undertaken by the Department for a radiation therapy service in the North West except one. A media article did make reference to consideration being given for a linear accelerator in the North West as an outreach of the Launceston Holman Clinic by the state government (Blewett 2007), however no further mention of this could be found.

The Plan also made reference to the fact that a framework for cancer services was under development and this would identify key areas of change and would address equitable access for all patients. The Framework referred to a model of delivery of cancer services, with the North West considered low to mid level in its service provision.

### *Health professionals (n=9 documents)*

The view of medical and health professionals and their representative bodies was varied in terms of national responses to extended cancer services in regional areas. The Senate's 2005 inquiry into services and treatment options for persons with cancer took evidence from a number of representative groups (Senate Community Affairs References Committee 2005). The Rural Doctor's Association of Australia (RDAA) raised concern over service fragmentation and lack of treatment facilities and options for patients in rural areas.

The RDAA highlighted that 'even when cancer is detected early, more country people are dying because of a service fragmentation and a lack of adequate treatment facilities in regional areas'. Witnesses reported that many regional and rural centres in Australia have only limited access to specialist cancer services. 'In the case of medical oncology, 86.5 per cent of medical oncologists are located in a metropolitan capital city, with a further 8 per cent in large regional centres and 5.5 per cent in smaller rural or remote areas' (Senate Community Affairs References Committee 2005, 60).

The RDAA also expressed concern over the lack of educational campaigns aimed at reducing the impact of modifiable risk factors, indicating a policy belief.

Modifiable risk factors have been identified for both. They include smoking, poor diet and nutrition, physical inactivity and excess weight, all of which are associated with living in a rural area. Yet few public campaigns to promote behavioural change in these matters appear to be adjusted for relevance to the rural environment or to engage people of lower economic or educational status. (Rural Doctors Association of Australia 2005, 3).

However, an overt value statement was that the need for regional patients to travel to cancer centres was 'almost inhumane', particularly in regard to travel and accommodation costs, indicating that this was a core belief of this group.

Many people undergoing chemotherapy will lose their hair and experience intense nausea. This makes the need to travel to distant centres for care almost inhumane, especially when patient support schemes do not all cover the full costs of travel and accommodation. Consequently the need to travel becomes a major determinant of poor cancer outcome, as many people have to make their health care choices on the basis of financial and social cost, rather than optimum healthcare. (Rural Doctors Association of Australia 2005, 4-5)

The group did indicate that having radiation therapy in smaller rural areas was 'impractical' but that such services should be built in larger regional areas with outreach services through the 'hub and spoke' model.

The National Breast Cancer Centre discussed the importance of multidisciplinary care (MDC) for cancer patients and the advanced outcomes for MDC when treatment was received in urban centres with higher caseloads (Senate Community Affairs References Committee 2005). The National Rural Health Alliance (NRHA) echoed this value, highlighting the rarity of MDC in rural and remote areas for cancer patients, largely because of lack of appropriate staff.

Regarding multidisciplinary care for rural areas, Mr Gregory, the Executive Director of the National Rural Health Alliance pointed out to the Committee

that the multidisciplinary cancer support team is rare in rural and remote areas. He emphasised that it is currently very hard to put together the necessary multidisciplinary team for cancer care. (Senate Community Affairs References Committee 2005, 45)

The NRHA made additional value statements relating to transport difficulties and costs for cancer patients, describing this as 'additional suffering', and stated that better facilities in rural areas was 'imperative', including radiotherapy (National Rural Health Alliance 2005, 6). No specific mention was made by any representative group of any requirements for extended cancer services in Tasmania.

The Clinical Oncological Society of Australia (COSA) made similar value statements in the mapping of oncology services report of 2006. COSA stated that improving cancer care for regional patients should become a 'rural health priority' because of the inequitable health outcomes for regional and remote areas.

More generally, the problems of diagnosing and treating cancer in regional Australia reflect disadvantages across the healthcare spectrum experienced by all rural and remote communities. Improved cancer care should be a rural health policy priority, because cancer as a disease group kills more Australians than any other cause and its impact is felt disproportionately in regional areas. The evidence indicates that reducing inequality in cancer outcomes requires a combination of improved primary healthcare and access to specialist multidisciplinary services. (Clinical Oncological Society of Australia 2006, 6)

COSA also touched on the importance of coordination of care and advocated for the construction of regional cancer centres of excellence, largely where radiotherapy infrastructure is already in place, which did not include any site in Tasmania. COSA did state, however, that Tasmania had two radiation therapy sites at that time, despite suggesting a population of 600,000 was needed to safely deliver such a service, and identified this as because of population requirements compared with the needs of the local community. This indicated a belief of COSA was that Tasmania had sufficient radiation therapy services at that time.



Radiation therapy is an expensive treatment to establish but is the most cost-effective treatment modality to administer once the infrastructure is established. There is a core requirement of a population base of 600,000 in order to justify a radiation oncology centre. There are two centres in Tasmania and one in the ACT, however, which highlight the interplay between population requirement and the needs of local communities. (Clinical Oncological Society of Australia 2006, 34)

Specific to Tasmania, health professionals made few statements but those made did tend to show sympathy for the level of services received in the North West region. One media report quoted a medical oncologist providing outreach to the North West from Launceston as saying he was 'fed up with inequities in services between North and South' to justify his move to the South (The Advocate 2007). The move was a consequence of a perceived lack of travel support by the state government. Statements made by the Director of the Launceston Holman Clinic were also critical of the role of the state government, stating 'North-West patients are getting a worse deal and there's a gross inequity of service; for example there's only one medical oncologist for all of Northern Tasmania' (Ford 2007b). This coincided with the Clinical Issues Paper produced by the state government, which looked at possible centralisation of services. Although cancer was not specifically mentioned in the Paper in this context, the Director made the statement that centralisation was not supported by the oncology community.

### *Community and community advocates (n=6 documents)*

The period prior to 2007 was largely absent of specific discussion by the North West community on the need for extended cancer services, but rather a focus on maintaining the level of services currently in place. The Richardson Review reflected public concern that the recommendations of the Review would be 'put on a shelf and forgotten', indicating a level of cynicism among the public in relation to health reforms (Expert Advisory Group 2004, 61). It is not known whether these sentiments were expressed through the submission process by members of the general public or by health professionals or community advocates. However, it is known that of the 190 submissions received 81 came from consumers or their advocates and 134 were focused on the North West. It is noted that none of these

submissions, however, focused on radiation therapy in the North West. Also of note is that the review of newspapers from that time by the Review did not identify radiation therapy in the North West as an issue of importance, or chemotherapy in any part of the state. The focus on North West hospital services in a majority of submissions was noted as the possible consequence of the operators of the Mersey Community Hospital announcing a change in its service provision the day before the Review's discussion paper was released.

The 2007 Clinical Services Plan resulted in regional communities most affected by planned changes expressing their opposition to those changes and supporting the continuation of existing services (Shannon 2010). In the specific context of cancer services, only one media article discussed community views where apparent miscommunication and misinterpretation resulting from the Clinical Services Plan had led some patients to believe that all oncology services might close in the North and North West, leaving all treatment only available in Hobart (Ford 2007b). The main concern raised was the need for patients to travel, rather than an inability to access these services, but no further specific statements were made.

Some North-West cancer patients fear for their medical services amid rumours that services will be centralised in Hobart. The Health Department yesterday said there was no consideration of that under the state Clinical Services Plan being developed. However, Ulverstone cancer patient Rodney Cooper said his doctor told him oncology services at the WP Holman Clinic in Launceston would go and cancer services would be centralised in Hobart, leaving critically ill North-West and Northern patients no choice but to travel south. (Ford 2007b)

Nationally, the Senate Inquiry of 2005 gave cancer patients an opportunity to relay their experiences, using such terms as feeling 'lost', feeling as though coordination of care was akin to a 'cancer lottery', feeling there was a lack of referral to support groups, and feeling the mental effects of a diagnosis were not recognised.

Cancer patients spoke to the Committee about the 'cancer lottery' starting at the point of diagnosis where they found the referral process ad hoc, with many finding specialists through serendipitous connections and word of

mouth. Patients wanted more information to be able to choose a specialist they felt comfortable with. Witnesses also reported their care had been fragmented and disorganised and individual support needs had not been met. Cancer patients wanted greater coordination of care along the care continuum through a multidisciplinary approach and combined with better support mechanisms. Cancer patients told the Committee how they experienced feeling 'lost' in the current cancer treatment system. (Senate Community Affairs References Committee 2005, 7-8)

Comments were also made that lent support to the notion that some patients chose not to travel for treatment.

Economic and physical barriers such as distance, lack of transport and the need to travel, impact on treatment choices for the rural cancer patient. Some people with cancer do not wish to travel away from their family and support networks to obtain treatment and may accept levels of treatment which are not going to give them the best chance of survival or the best results. (Senate Community Affairs References Committee 2005, 61)

#### ***Media (n=1 document)***

Media articles were a frequent source of value statements and expressed beliefs of major actors involved in this policy subsystem. However, only one represented a direct view of the media itself, rather than providing quotes from other major actors. One article mentioned that the loss of the outreach medical oncology service to the North West, when the only Northern based specialist relocated to Hobart, would result in patients being 'forced' to travel to Hobart (The Advocate 2007). The use of the word 'forced' indicates emotive language and the framing of a particular narrative. No further media articles were found representing direct discussion of the need for extended cancer services.

In summary, the period of 2000-2007 was one of some discussion at a federal level around the best way to deliver cancer services to people across the country. However, no specific discussion of radiation therapy services in North West Tasmania was noted.

## Nov 2007–Aug 2010

The period between the federal elections of 2007 and 2010 is marked by a considerable increase in discussion relating directly to extending cancer services in North West Tasmania. This was notable among those elected to the state Parliament, on both sides of the House, as well as the media. However, it was largely free of discussion and analysis among researchers and commentators. Overall themes continued to be safety and sustainability, travel, multidisciplinary care, coordination, staffing, transport and accommodation, equity, education and support services, with the inclusion of one new value (or perhaps political strategy) around expediency (see Table 17).

**Table 17 Evidence of beliefs by major actors, Nov 2007 –Aug 2010**

	<i>Federal n=9</i>	<i>State n=16</i>	<i>Health Prof n=5</i>	<i>Community n=9</i>	<i>Media n=6</i>
<b>Coordination</b>		✓			
<b>Support</b>		✓			
<b>Travel &amp; Transport</b>	✓	✓	✓	✓	
<b>Safety and sustainability</b>	✓	✓	✓		
<b>Centralisation versus maintenance</b>					
<b>MDC</b>		✓			
<b>Equity &amp; access</b>				✓	
<b>Politically driven change</b>					
<b>Staff skills</b>					
<b>Duplication</b>					
<b>Recruitment &amp; retention</b>		✓			
<b>Health budget</b>	✓				
<b>Community Expectations</b>	✓			✓	✓
<b>Urgency of the issue</b>		✓			

### *Federal health policy actors (n=9 documents)*

This period was relatively devoid of any discussion by the federal government or federal opposition in relation to extended cancer services for North West Tasmania up until the start of the federal election campaign of 2010. In late 2009 the federal government opened the Regional Cancer Centres Initiative, a \$560 million fund for the establishment of regional cancer centres, and Burnie was considered well placed to receive a favourable bid (Bingham 2009b). Approximately \$5 million was provided to establish a cancer centre at the Burnie-based North West Regional Hospital in May 2010, which included chemotherapy chairs, consulting spaces and a part contribution for an MRI but did not include funding for a linear accelerator (The Advocate 2010f). This quickly moved into a period of accusation by state and federal Liberal opposition. The federal Labor government responded by placing blame squarely at the feet of the Tasmanian Labor government, stating in July 2010 that North West Tasmania only lacked access to radiation therapy services because the Tasmanian government had not applied for funding for this service.

‘The Tasmanian government did not make an application to the federal government for funding support for radiotherapy services here in the northwest when we sought applications under our regional cancer centres program,’ Ms Gillard told reporters. ‘We are standing ready and able to consider an application from the Tasmanian government. ‘If an application is received, it will be considered immediately and sympathetically.’

(News.com.au 2010)

Statements then moved onto election commitments from all sides of politics during the height of the federal election campaign. In August 2010, on the eve of the public forum held in Burnie, the Abbott opposition announced an \$85 million health infrastructure fund, with the first commitment being \$7 million towards a linear accelerator in North West Tasmania (ABC News 2010c). In his media conference, Mr Abbott accused the current member for Braddon of having promised a linear accelerator in 2007 but ‘failing’ to deliver on this. When speaking of the distances travelled, Mr Abbott stated, ‘People deserve better than this’. When questioned on the lack of state government readiness to install a linear accelerator Mr Abbott referred to the state’s own Cancer Strategic Plan, which identified the need for an

additional linear accelerator from 2013 and stated 'it would be a pretty foolish state government that didn't want to cooperate with us' (Abbott 2010). The Liberal opposition also went on to match funding from a local businessman to establish radiation therapy scholarships for the North West region (The Advocate 2010b). The response of the Labor state government was that the funding commitment had not been discussed with the state prior to the announcement (The Advocate 2010a).

The commitment by the ALP for \$16.5 million for a linear accelerator and associated infrastructure was made 3 days after the Liberal commitment but the federal Health Minister added that the service would only be established when the state government deemed it safe to do so.

Roxon announced a \$16.5 package at the North-West Regional Hospital in Burnie today for "fast-tracking" the infrastructure for a linear accelerator (sic). However, Ms Roxon said the radiotherapy services would only be brought in line when the state government deemed it safe. Ms Roxon announced a panel of local people and medical experts (sic), expected to be chaired by Devonport businessman Royce Fairbrother, would decide when the service was to be brought online. The announcement comes on the back of the federal opposition leader Tony Abbott announcing in Braddon last week a linear accelerator would be operational for the region by 2013. The state government had pledged cancer services for the region by at least 2016 before the state election, but then backed down on that promise later. Ms Roxon said today Mr Abbott's date of 2013 was not achievable. (The Advocate 2010e)

### ***State health policy actors (n=16 documents)***

Document analysis found no statements by or relating to the Tasmanian government or opposition in regard to extending cancer services in the North West during the period of 2008. The majority of discussion centred on the latter part of 2009 and into 2010, in particular the release of the Cancer Framework and Strategic Plan 2010-2013 and debate over the need for radiation therapy services as part of the federal election campaign.

*The Cancer Framework and Strategic Plan 2010-2013* in itself gives an indication of the values and priorities of the then Labor state government. Beyond screening and detection, emphasis was placed on proper coordination of services and sustainability.

There is a significant opportunity to improve coordination of services for people affected by cancer. This requires improvements in the way services are designed and in the links and referral processes between diverse service providers. (DLA Phillips Fox 2010, 23)

Multiple references were made to overcoming travel barriers for regional patients by enhancing transport and accommodation services, as well as multidisciplinary care, education and support services. The Plan did acknowledge that the North West received a number of outreach services and that these were 'not organised systematically' and tended to be 'unsustainable' (2010, 20). The Plan highlighted that funding needed primarily to ensure service sustainability. With specific reference to cancer services in the North West, the Plan did state that given its population size the region would benefit from cancer services provided from Burnie or Devonport, but acknowledged that the cost of equipment and the staffing required made radiation therapy difficult to provide outside of the outreach model.

Because of the cost of the equipment, radiation oncology services usually are located in major centres, although this is changing with the advent of single machine units. Radiation therapy is available in Launceston and Hobart at present. An additional linear accelerator, funding for which was approved in the 2009/10 federal budget, will be installed in Launceston.

A variety of outreach cancer services are provided to the North West region- for example, radiation oncologists and haematologists/medical oncologists from both Hobart and Launceston visit the North West region on a regular basis to provide consulting services to people who live in those areas. These services are not organised systemically, however, and have tended to be unsustainable in the past because of their dependence on key individuals. Arrangements for their funding vary and have not been established

systematically with the primary purpose of ensuring service sustainability.

(DLA Phillips Fox 2010, 20)

It stated that linear accelerators would be needed in time but that the location of these would need to consider demand and referral rates. A unit in the North West was considered possible once needed if supported by a three-machine service out of Launceston.

In May 2009, the state government announced that it had recommended that the third linear accelerator promised for the Northern part of the state in 2007 would be located in Launceston (Blewett 2009). The article claims the decision was actually made in November 2008 but held for six months before it was announced. In an undated report from the Tasmanian government's Contract Review Committee obtained under Right To Information (estimated to be from the first half of 2008 because of the estimated funding commencement date of 1 July 2008) the details of the decision to base a third linear accelerator in Launceston were outlined. In it the Committee stated

the recommended option is for the installation of a third linear accelerator at the LGH Holman Clinic to enhance the existing service with capacity to manage increased workload and it is believed that this would also improve the opportunities for the recruitment of key personnel as well as some economies of scale with staffing and equipment needs. (Contract Review Committee n.d., 3)

The report discussed concerns with the sustainability of single machine units, recruitment and retention issues and the need to duplicate other services, such as simulation, planning and licencing related to the North West, thus making the Launceston Holman Clinic the preferred location.

It is expected to be more difficult to recruit to the North West Coast and one of the potential risks with a new North West centre is that specialised staff attracted to this area may come from within the existing staff at the LGH. This may produce a situation where both centres are understaffed and this would significantly impact service delivery in both centres and also limit the



Launceston Clinic's ability to provide the necessary support to an outreach centre. (2)

It was also considered to limit the need to act on a fourth possible linear accelerator until 2015 at the earliest.

In October 2009 the state government was again forced to defend its role in providing support to the same medical oncologist who had moved from Launceston to Hobart in 2007, creating a vacuum in oncology services. The oncologist officially resigned and left the state, seemingly because of the state government's refusal to accommodate his request to work part time in Hobart and part time providing outreach to the North West, a move the Liberal state member for Braddon called 'stubborn'.

The stubborn approach of this Minister will lead to even more holes in the health system, including no medical outreach service in the North-West and no additional oncology help at the RHH. (Whiteley 2009)

When the Regional Cancer Centres Initiative was announced in late 2009, then Health Minister Lara Giddings described the view of the state government as 'very keen to further extend oncology services in the North-West' and suggested it was in keeping with what the state government had been planning for the North West for some time as part of the Clinical Services Plan (Bingham 2009b). Radiation therapy was not mentioned. The Liberal opposition also voiced their commitment to ensuring a new cancer centre was built in the North West through the Initiative, but instead placed their emphasis on expediting such a service, saying that a Liberal state government would have the centre, including a linear accelerator, built by 2012 as opposed to 2016 (Pippos 2010). These statements were made in the lead up to the Tasmanian state election in March 2010. Then Premier, David Bartlett, responded by promising an additional \$10 million on top of the funding received through the Initiative to 'speed up' the provision of comprehensive cancer services.

With the state election to be called today for March 20, Mr Bartlett said the Labor plan would end the need for North-West cancer patients to travel from the region for most services. 'And we will do it sooner than the Liberals.' The Labor plan had previously been to have the full services in place by 2016 or

later, but Mr Bartlett said yesterday the new funding meant he now expected it would be well before then. (Ford 2010)

This included a linear accelerator 'as soon as possible' and indicates the importance that state candidates were placing on the speed at which cancer services could be delivered to the region as well as specifically introducing mention of a linear accelerator to the policy debate. However, by June 2010 after the state election, a linear accelerator was not yet considered possible by the state government until a critical mass of staff expertise in Launceston was achieved.

As I was saying, the program will deliver \$16.5 million for the North West Regional Hospital and will see construction start this year on a new acute cancer care centre for the north-west. The new facility will offer an extensive range of acute services, including an MRI scanner, 12 chemotherapy chairs, separate consulting rooms, a base for outreach palliative care, and educational facilities for the Rural Clinical School and the north-west GPs as well for the community. The building will be designed to accommodate a future bunker for the proposed north-west linear accelerator.

I do appreciate that there are currently patients travelling to Launceston to receive radiation oncology services. The viability and safety of an isolated single machine radiation oncology unit in the north-west will become a possibility when the critical mass of high specialised staff is achieved at the Launceston General Hospital's Holman Clinic with its third linear accelerator, if cancer rates grow as projected, and if referrals of people with cancer for radiation oncology reach the nationally recommended rate of 52.3 per cent. (Tasmania 2010c, 45-46)

Until then, Launceston would continue to provide 'safe, high-quality treatment' for North West residents (Speers 2010).

When the federal Coalition commitment for a linear accelerator for the North West was made in August 2010, the state Health Minister indicated that this had not been discussed with the state government, nor had any policy detail been provided, particularly on capital

and recurrent funding, indicating the view of the state government on maintaining division of responsibilities as well as the inadequacy of the funding commitment (The Advocate 2010a). Media coverage ensued on whether the Labor state government had committed to providing radiation therapy services in the North West by 2012, with the local newspaper citing Treasury documents to say it had, while the Health Minister said they had simply promised to deliver such services 'before the Liberals' (Livingston 2010).

After the community petition was presented to state Parliament in September 2010, the accompanying speech by the Liberal member for Braddon, Jeremy Rockcliff, used such emotive terms as 'the greatest con', 'treacherously betrayed', 'second-rate citizens' and 'political pawns' to describe Labor's change in support for a radiation therapy service prior to 2012 (Tasmania 2010a). The member cited long travel times for patients, separation from family support networks and comparatively poorer health outcomes for regional areas as the main reasons to support a radiation therapy service in the North West and accused the state government of delaying the clinical expert panel established to determine the best design for radiation therapy in the region.

What the government appears to want to do, and I believe for purely obstinate reasons, is design a cancer centre and deliberately delay the advice from its expert clinical panel about whether or not to include radiotherapy services in the centre until after the design has been done and submitted to council. (Tasmania 2010a, 56)

In response, the then Health Minister cited safety and sustainability and lack of specialist staffing as the main reasons for delaying a radiation therapy service and used such language as 'irresponsible' and 'fragile' to describe the system and enshrining timelines for radiation therapy into legislation (Tasmania 2010a). The Health Minister also made clear that equity could not be considered in isolation from safety and sustainability.

I must say, in terms of the issue of equity that Mr Rockcliff raised in his contribution, equity is a very important point and we believe that it is only equitable to be providing safe and sustainable services and that it would not be equitable to put in place services that were unsafe. That is not what equity is about. (Tasmania 2010a, 65)

### *Health professionals (n=5)*

The view of the medical community was only represented in document analysis by the AMA and only during the period of 2010. The AMA continued to express values and beliefs centred on safety and sustainability. In January 2010 the AMA released a media statement, saying that radiation therapy should not be a part of any expansion of cancer services in the North West. This was because of the issue of recruitment and retention of specialists who were considered in short supply in Australia.

It is not just that linear accelerators are complex machines that are expensive to install and maintain. The major difficulty will be the recruitment and retention of the highly specialised staff necessary to implement and maintain the service. Such a service requires radiation oncologists, specialised nurses, radiation therapists, engineers, medical physicists and other technical staff. All of these personnel are in short supply in Australia. (Australian Medical Association Tasmania 2010c)

The statement also outlined the AMA's belief that a population of less than 250,000 was not feasible to support such a service, citing issues with the Latrobe Valley service to highlight their concern. The AMA proposed strengthening transport and accommodation support in order to assist patients from the region to access radiation therapy from Launceston. After the federal Liberal commitment for a linear accelerator in August 2010, the AMA's response was initially one of 'cautious welcome' and the organisation stated the need to 'look at the figures'.

The election promise by the opposition leader the Hon. Tony Abbott made on 6 August in Devonport to fund improved cancer treatment services for the North West of the state has been cautiously welcomed by AMA Tasmania. But unfortunately, when measured against AMA criteria for closeness to patient care, safety, and sustainability, the establishment of a linear accelerator service in Burnie fails the last two. (Australian Medical Association Tasmania 2010b)

However, three days later the AMA reverting to its prior stance that the region lacked the population to warrant such a service and that it would in fact jeopardise the viability of the Launceston service.

But Michael Aizen from the Australian Medical Association says even with patients travelling from the region to Launceston to use the machine there, that service is barely sustainable. 'If we were to further fragment services across the state, then we may end up seeing two, not one, non-viable services,' he said. (ABC News 2010a)

The AMA suggested that the funding should instead be directed towards improving transport and accommodation and that a linear accelerator not be considered until 2016 (Livingston 2010).

### *Community and community advocates (n=9)*

The period of 2010 became one of some specific action by members of the community in relation to extending cancer services in the North West. There was no evidence of direct action prior to 2010. In early 2010, a local philanthropist donated \$1.3 million as half the funds required to purchase an MRI for the North West Regional Hospital, which was considered a key piece of cancer equipment. The donor expressed concerns over 'travel and inconvenience' as the catalyst for the funding.

'I think that's a very good thing and I think our community should have those sorts of facilities in Burnie or on the North-West Coast,' Mr Elphinstone said.

'It prevents people that have those sorts of problems having to travel and be inconvenienced'. (Pippos 2010)

The same philanthropist later committed \$600,000 bonded radiation therapy scholarships to ensure properly trained specialists would be available to work in the region and to provide a 'complete solution' to residents of the North West (The Advocate 2010b). He also went on to state that the medical community should 'keep out of the way' (The Advocate 2010g) and that he was 'sick of hearing excuses to justify why radiotherapy at the North West Regional Hospital cannot happen' (Bingham 2010b).

In August 2010 a community forum was held in Burnie and arranged a facilitated by a local Councillor. This Councillor stated that travel was 'an emotive issue' but 'something that needs to be looked at' (ABC News 2010a). The same Councillor arranged a petition, which was presented in state Parliament in September 2010 (after the funding commitments for a linear accelerator). In it, the petition stated

that the citizens of the Electorate of Braddon strongly believe that it is unfair and inequitable for hundreds of patients from the North-West Coast to travel two to three hours to Launceston or four to six hours to Hobart; and patients from the West Coast to travel three to four hours to Launceston or six to seven hours to Hobart, to access essential cancer treatment. (Citizens of Tasmania 2010)

The petition went on to ask that the state government immediately consider a Braddon Cancer Treatment Centre that included radiation therapy. The petition bore the names of 6760 petitioners as was referred to as one of the largest presented to the Tasmanian Parliament (Tasmania 2010b). A media article also made reference to a FaceBook group called 'Cancer Treatment with Radiation for Braddon NOW', which had attracted 1300 members in a 24 hour period (The Advocate 2010c) but no further details of this group could be found to establish values or beliefs.

### **Media (n=6)**

Media reports, mainly from the local newspaper, were consistent during the period of 2009 to 2010 and all demonstrated a strong level of support for extended cancer services in the North West. The issue was considered to be 'a hot political issue' (Bingham 2009b), made more so by the denial of a linear accelerator in 2007, and the state government was accused of 'putting off' providing a such a service to the region (Livingston 2010). The eventual funding announcement was received as 'long awaited' (Bingham 2010a). A particularly strong expression of belief came in the form of an editorial published in *The Advocate*, in which the reporter stated

Premier David Bartlett, you have gone too far. Apparently you have been liberal with the truth to get votes on an issue you knew meant so much. From

what we can see, you are not even trying to provide radiation therapy at the North West Regional Hospital until 2016... Mr Bartlett and the health minister cannot get away with trotting out the old line, that it is not safe or viable. We have heard it all before. Ditch the tired old arguments that won't wash with us any more and find a model that works and make it happen well before 2016 as you damn well promised... Labor's Braddon MPs, perennial backbencher, Brenton Best and prodigal Labor son, Bryan Green, should hang their heads in shame for winning votes on what so far is nothing more than the same hot air. (cited in Tasmania 2010a)

In summary, the period 2007-2010 saw most discussion concentrated towards 2009 and 2010, in the lead up to both the Tasmanian and federal elections of 2010. The introduction of the Regional Cancer Centre Initiatives led the way for future funding commitments, which would impact on the policy debate. Discussion in relation to radiation therapy in North West Tasmania occurred late in this period.

#### *Aug 2010–Nov 2015*

The period between the federal election 2010 and late 2015 was marked by debate between major actors on the design of the North West Regional Cancer Centre and the best method for delivering radiation therapy services to the region. This period also coincided with attempts by the Tasmanian government to restructure public health services through the One Health System White Paper. The main values and beliefs expressed were: safety, sustainability, travel and accommodation, support services, regionalism and parochialism, political decision making, coordination of care, screening, prevention, communication, duplication of services, staffing, technology, competing funding priorities, minimum standards, clinical need and community expectations (see Table 18).

**Table 18 Evidence of beliefs by major actors, Aug 2010 – Nov 2015**

<i>Belief</i>	<i>Federal n=7</i>	<i>State n=25</i>	<i>Health Prof n=12</i>	<i>Community n=9</i>	<i>Media n=4</i>
<b>Coordination</b>		✓	✓		
<b>Support</b>			✓		
<b>Travel and Transport</b>		✓	✓	✓	✓
<b>Safety and sustainability</b>	✓	✓	✓		
<b>Centralisation versus maintenance</b>					
<b>MDC</b>					
<b>Equity and access</b>				✓	
<b>Politically driven change</b>			✓	✓	
<b>Staff skills</b>		✓			✓
<b>Duplication</b>			✓		
<b>Recruitment and retention</b>		✓	✓		✓
<b>Health budget</b>			✓		
<b>Community expectations</b>	✓	✓		✓	✓
<b>Urgency of the issue</b>				✓	

### ***Federal health policy actors (n=7)***

After the commitment was made by the ALP to fund a cancer centre and radiation therapy as part of the 2010 federal election campaign, final approval by the Health and Hospital Fund was announced in September 2011 after the Clinical Expert Panel delivered their report into the need and best design for radiation therapy services (Bingham 2011a). The federal member for Braddon indicated the federal government's position on this issue by stating that the Report had proven the case for radiation therapy services and there now existed an obligation to provide it (Bingham 2011a). The member stated that he had been integral in the funding commitment by having 'worked closely with the Minister for Health and Ageing to deliver this project' (Dolan 2011). This was in contrast to his earlier stated position that the North-West had not received the third linear accelerator in 2007 with the region 'not able or capable of providing those services without a lot more investment both from the



state and the Commonwealth', something the member noted was 'viewed as a broken promise, particularly on my part' (Australia 2010, 2437). In the same speech, the member went on to discuss the need to deliver 'safe and reliable services', indicating that this was still seen as a core value and that the current commitment was meeting this. There were no further discussions or belief statements made on this issue by the federal government, opposition or candidates.

### *State health policy actors (n=25)*

The period 2010-2015 was one of high activity between major actors in the policy debate given the construction of the North West Regional Cancer Centre, as well as a state election, major health cuts and the One Health System reforms. Over this period up until the state election of 2014, the Health Minister was forced to publicly comment on: quarantining the Centre from health cuts (Bingham 2011b); waiting for confirmation of funding by the Health and Hospital Fund (Dolan 2011); the ability to recruit the necessary specialist staff (Bingham 2011a); and her admission that the state government did not have the operational funding for the Centre in the Budget upon the confirmation of the federal funding (Bingham 2011c). One state MLC went as far as to comment that 'the community would revolt' if the Centre did not open and that it was 'political suicide for the state government to build a cancer centre, which its own expert panel says is needed, and then not use it or delay using it (Bingham 2012). The Health Minister reiterated that the funding would be committed when the service was ready to be safely delivered, bringing the focus on safety back into the policy debate. She also stated that quarantining such funding so early on would be 'ludicrous'.

'Jeremy Rockliff appears to be suggesting we find the money to staff a service that won't be ready for several years from this year's operational budget-cut services now to fund recurrent costs that don't even exist yet, the idea is ludicrous,' she said. (Bingham 2012)

Operational funding was not committed until the Budget of 2015, when the new Health Minister stated 'after many years of Labor governments expecting Tasmanians to accept a broken health system, we are now heading in the right direction' (Ferguson 2015).

Upon release of the Clinical Expert Panel report (North West Radiotherapy Clinical Expert Panel 2011) there was almost unanimous agreement that the Report gave unconditional approval to the construction of the Centre and confirmed the need once and for all for a radiation therapy service.

It follows the Tasmanian health minister's release of a definitive clinical expert panel report almost a month ago, which said North-West patient numbers not only justified a linac machine at the NWRH now but two linacs would be needed by 2021.

The Clinical Expert Panel report ended any questions about if a radiotherapy service was needed in Burnie, said the North-West Area Health Services boss.

State Liberal health spokesman Jeremy Rockliff said yesterday he would expect a positive decision from the HHF board given "the unequivocal commitment made by the federal Labor government last year'. (Bingham 2011d)

The state government stated in its submission to the Parliamentary Standing Committee on Public Works that the Centre represented 'an appropriate level of health services for the community', indicating that radiation therapy was now considered the minimum standard for the region (Department of Health and Human Services 2012b, 32). This was a view reinforced by the Tasmanian Health Minister, who stated 'We are committed to providing that service there. It's an expensive build, it's a good service and we think it's sustainable' (Bingham 2014a), indicating that this issue of sustainability was ostensibly resolved for the state government.

The report from the Parliamentary Standing Committee on Public Works on the North West Regional Cancer Centre incorporated numerous statements from various actors across different groups on cancer service provision in the North West region. Health bureaucrats commented that the provision of an MRI, partly through a private donation, would save travel of an hour and a half by patients to Launceston as well as improving capacity at the Launceston site and reducing wait times. The same bureaucrats indicated that travelling for radiation therapy was a 'substantial burden'.

From the patients' point of view, the people of the north-west travelling for an hour and a half to have a minute of treatment and then travelling an hour and a half back is a substantial burden. For those patients who elect to take the free bus that is provided very graciously by the Cancer Council, the patients have to wait for all the other patients on the bus to have their treatment. Sometimes that is an impost of around six and a half hours on their day, so it is a big difference from a patient point of view. From the state's point of view, it is going to meet an ongoing need for these services which, as you heard earlier this morning...some of the anticipated growth for these patients is around 30 per cent for the state as we are an ageing population with chronic and complex needs. (Austin cited in Parliamentary Standing Committee on Public Works 2012)

2012 saw the introduction of the Tasmanian Cancer Model of Care Draft. In this, the state government reiterated values around the need for coordination of care, access to transport, accommodation, information and support services, safety and multidisciplinary care.

Treatments for cancer are becoming increasingly multimodal and require an appropriate mix of surgery, chemotherapy, radiotherapy and other treatments, which requires patients to see multiple specialists. This can lead to people negotiating a maze of diagnostic, treatment and support services which gives rise to a complex and sometimes confusing journey. This complexity necessitates a high level of coordination in how cancer care is designed and delivered. The Tasmanian Cancer Model of Care seeks to provide an underpinning set of principles to help coordinate and guide the delivery and planning of cancer care in the state. (Department of Health and Human Services 2012e, 5)

The Draft did not, however, discuss the concept of delivering services as close to local areas as possible when the concept of access was discussed, indicating that access was considered in terms of getting patients to services rather than services to patients. This view was further supported in the Department of Health and Human Service's submission to the federal government's Review of Funding Arrangements for Chemotherapy Services. The submission

reiterated that 'the issues of cost and difficulty in recruiting/retaining specialist staff (Oncologists, Pharmacists and Nurses) in rural and regional areas mean that in Tasmania chemotherapy for cancer is provided in metropolitan and major regional centres only' (Department of Health and Human Services 2013b, 7). The state opposition disagreed with this view of North West capacity to sustain services, stating instead that chronic disease rates provide an evidence base upon which to support local provision of cancer services.

If you look at the West Coast cancer rate (which is above the state average) and if you look at the region's chronic disease rates, that kind of evidence-based provision of services will work well in favour of the North-West Coast. For example, there are some Southern clinicians that dismissed the need for the cancer centre in Burnie and I would disagree with them based on the evidence. (Rockcliff cited in Bingham 2013b)

This was contradicted somewhat by the statements of the incoming Tasmanian Health Minister in 2014. The state election of 2014 resulted in a change of government from ALP to Liberal and with it came the One Health System Green Paper and White Paper, which looked at a restructure of the Tasmanian health system, similar to that of the 2007 Tasmanian Health Plan. The plan was underpinned by the sentiment that health service provision needed to shift.

The government recognises that this is a complex exercise, requiring a balance between local access, quality, safety and sustainability on a whole-of-state basis. However, it is a necessary exercise. If we are to provide safe, effective and sustainable services in Tasmania, we need to shift the discussion from simply 'better access to services', and instead strive towards 'access to better services'. This needs a recognition that we cannot afford – either financially or in terms of the safety and quality of services – to provide all services in all locations. We must determine the best profile of services across the state to ensure equal access to quality services for all Tasmanians, regardless of where they live. (Department of Health and Human Services 2014a, 3)

The Green Paper identified the importance of minimal service volumes, safety and quality, overcoming regionalised views of health service provision, transport and accommodation as the key to accessibility, utilisation of technology such as telehealth and coordination of care – all sentiments expressed by the previous state government. The subsequent White Paper Draft specifically discussed the entrenched issue of recruitment of oncology staff in the North West and stated that ‘this will be exacerbated by the planned delivery of radiation oncology services locally in this region’ (Department of Health and Human Services 2015a, 26). The Draft went on to propose a ‘hub and spoke’ model with shared staff rotated between Launceston and Burnie as part of the Northern Integrated Cancer Service, something that had been proposed 4 years prior in the Clinical Expert Report. This was stated in the final White Paper as the answer to safety and sustainability and labelled the previous delivery of oncology services via a fly-in, fly-out specialist as a ‘failed regional model’ which did not meet national standards (Department of Health and Human Services 2015b, 24). The ALP, now in opposition, responded to the White Paper by stating that ‘centralising services is not something we’re particularly keen to see, as it might severely disadvantage people living in rural and regional areas’ (Smiley 2015a).

### *Health professionals (n=12)*

Public statements by health professionals on this policy issue during this period fell largely into two categories – media statements by professionals or representative groups and participation by health professionals on panels.

Immediately following the 2010 federal election the AMA Tas welcomed the decision of the state government to fund two medical oncologists in the North West, saying it would ‘bring the level of cancer services in the North West to that in other parts of the state’ (Australian Medical Association Tasmania 2010a). However the AMA went on to publicly state that it did not believe the North West Regional Cancer Centre could be adequately staffed because of a nationwide shortage of medical oncologists (Dolan 2011). The AMA continued to express opposition to the Centre throughout its construction, stating in 2014 that the decision to put out a tender for a linear accelerator was a ‘mind-numbingly stupid decision’ because of a lack of clinical need for such a service in the North West, budget restrictions, staffing issues and the need for funding to be better utilised elsewhere (Stephens 2014). The AMA

expressed a belief that Tasmania would be better served per head of population than any other place in Australia should the linear accelerator go ahead.

AMA state president Tim Greenaway said the accelerator, which provides radiation therapy, would be difficult and expensive to staff, and he didn't feel there was a clinical need to have such a machine on the North-West. 'Per head of population, if that goes ahead, Tasmania will be by far better served in terms of population numbers per linear accelerator than any other place in the country,' Dr Greenaway said. 'All this will do is suck up precious funding from the North-West, which they need for other services like mental health nurses and child health nurses' (Stephens 2014)

In a letter to the editor of a local newspaper, a medical practitioner previously based in the North West claimed that the Centre was not a 'well-planned addition' based on health needs but rather the result of a political bribe.

The state government is quite happy to close wards and let waiting lists blow out when the money dries up. It withholds our tax dollars to spend wherever the votes can be picked up rather than where it's needed most. Previous elections have seen bribes for our vote including the federal buyout of the Mersey hospital and the cancer centre in Burnie. Great for the Coast? Yup. Well-planned additions based on our health-care needs? Not so much.  
(Wilson 2013)

The overall view of the health professions on the provision of radiation therapy in regional areas was the subject of some considerable debate during this period. In 2012 a joint strategic plan of the Australasian College of Physical Scientists and Engineers in Medicine, the Royal Australian and New Zealand College of Radiologists and the Australian Institute of Radiography noted that investment in regional cancer centres had resolved some issues relating to access. However it had also raised issues relating to workforce recruitment and retention, safe delivery of services, travel to metropolitan centres, and the use of telehealth and other technologies.

The recent establishment of a number of regional cancer centres has partly addressed some of the access issues for those living outside metropolitan

areas. At the same time these developments have highlighted some of the associated issues and risks, which include

- the attraction and retention of the workforce;
- the need to develop models of care that define what may be appropriately and safely delivered locally;
- the need to develop and enhance telemedicine and other new technologies in this sector; and
- the need to ensure that patients are not disadvantaged if they still need to travel to metropolitan centres.

Specific incentives and support programs will be required to further enhance regional and rural radiation oncology services. (2012, 4)

The Royal Australian and New Zealand College of Radiologists stated two years later that some rural patients were foregoing treatment because of the burden of travel.

Many rural cancer patients are refusing lifesaving radiotherapy because they can't afford time away from their farms or families to travel to major cities for up to seven weeks.

'People who have appropriate indicators for radiotherapy are missing out on their treatment,' Royal Australian and New Zealand College of Radiologists president Chris Milross said. Professor Milross applauded the previous Labor government for providing \$560 million to set up 26 regional cancer centres. 'The day they opened they were fully booked and we have to look to providing more linear accelerators in them,' he said. (Dunlevy & Crawley 2014).

The article went on to state that 40 new linear accelerators would be needed by 2017, with one third needed in rural and regional areas. This view supports and contrasts with other research focusing on travel by radiation therapy patients. A study in the United Kingdom found that although there was evidence of a psychological impact on patients who had to travel to treatments, there was no evidence to suggest that this in any way impacted on their take-up, compliance or continuation with treatment (Payne, Jarrett & Jeffs 2000). In an Australian context, although no evidence was produced proving the opposite, there were

comments that travel was an 'extra burden' to rural patients and that the physical effects of radiation therapy, such as burns and fatigue, needed to be addressed (Hegney et al. 2005). The relevance of this to Tasmania, however, needs to be considered. One review of cancer service delivery to rural and remote communities specifically excluded Tasmania as it did 'not have the extent of 'remoteness' found in other states' (Adams et al. 2009, 7).

The Clinical Expert Panel was formed by the Tasmanian government to specifically address the need for radiation therapy in the North West as well as the best design for delivering a safe and sustainable service. The Panel consisted of six health professionals and one community representative, a North West business man who was also a past cancer patient (North West Radiotherapy Clinical Expert Panel 2011). The composition of the Panel, with a high ratio of health professionals, indicates that the Panel's comments would be recognised as a health professional's view. However the impact of the community perspective via its one representative cannot be fully known or dismissed. The key findings included: sufficient caseload to justify one linear accelerator at that time with likely need for a second; a lower than average utilisation rate for radiation therapy (42.5% in the North West as opposed to 52% nationally); and travel to Launceston considered a major issue to people in the North West.

The Clinical Expert Panel considered that a stand-alone service was an 'unacceptable risk' and a recommendation was made to have a North West service linked to a Northern-wide multidisciplinary service, the existing Launceston facility. The Panel called for immediate action on coordination of care, travel and accommodation services and support services, continuing with the health perspective of these are key values.

Priorities for cancer services to be addressed in North West Tasmania identified through stakeholder consultations (not presented in order of priority) were

- reducing the burden on patients who have to travel for radiotherapy services (various options ranging from improving transport/accommodation options to local provision of radiotherapy)
- improving coordination of care and access to cancer services



- improving access to information about treatment and support services
- improving medical oncology and malignant haematology services in the region
- improving a range of other relevant services, including palliative care, access to physicians and general medical and support services
- improving overall governance of cancer services within the region and networking across the state (North West Radiotherapy Clinical Expert Panel 2011, 22)

While the Panel discussed burden of travel in terms of how residents of the North West perceived it, rather than how the Panel perceived it, the Melbourne-based medical oncologist providing outreach oncology services to the North West was more direct in her view of the burden of travel. The Oncologist stated to the Parliamentary Standing Committee on Public Works that patients experienced nausea during their travel, compounded by the radiation therapy, which could persist for months. The Oncologist further stated that they knew directly of patients who had discontinued their treatment as a direct consequence of the burden of travel.

For patients who have radiotherapy, for example, and travel to Launceston at this stage, they may feel very sick and experience nausea on the trip. For those patients who already have travel sickness, that will be compounded by the radiotherapy effects. The effects of this nausea may last for several weeks or months after their radiotherapy, so for additional trips they may have for consultation that would be a burden for them... I have had a few patients who have had to discontinue treatment because of the burden of travel and the illness associated with it. (Sim cited in Parliamentary Standing Committee on Public Works 2012, 7)

After the adoption of the Clinical Expert Panel's recommendations, and after the change of state government in 2014, the One Health System reforms were introduced into the health subsystem. In response to the Green Paper, the Cancer Clinical Advisory Group (CCAG), comprised of key health professionals involved in the provision of cancer services in

Tasmania, provided a submission to the state government. In their submissions the CCAG highlighted the importance of partnerships, collaboration and coordination of care as well as transparent communication.

There must be a requirement for clear and transparent communication to the public to address the reasoning on why specialised cancer services will be provided at specific locations. Transport and accommodation infrastructure and education for patients and family needs reform, as many patients may be transferred between hospitals when their level of care needs to be escalated or de-escalated, and careful assessment of capacity to ensure that higher level services can cope with the overflow/transfers from lower level services.

(Cancer Clinical Advisory Group 2014, 4)

The CCAG also considered the provision of chemotherapy services at the Mersey Community Hospital to be an 'unnecessary duplication of services' already provided at the North West Regional Hospital and to be provided at the Centre. They considered efforts and resources to be best focused on strengthening screening and prevention.

The AMA Tas also responded to the proposed changes of the One Health System reforms. The group supported the Tasmanian Health Minister's efforts to consolidate some services for better patient safety.

The Australian Medical Association's Tim Greenaway said the state health changes were well overdue. 'Too often there's been parochial politics that have played a role in destroying attempts at change,' he said. He agreed that Mr Ferguson's plan to consolidate very complex surgeries was a good policy and would improve patient safety (Smiley 2015a).

This continued the AMA's stance of supporting efforts by successive state governments to reform health services to promote efficiency and safety.

### *Community and community advocates (n=9)*

The period 2010-2015 saw an increase in the number of statements by community members and advocates, typically through the print media, in relation to cancer services in the North West region. The views expressed were consistently in support of the construction of the

North West Regional Cancer Centre, exemplified in one article that highlighted the community had raised in excess of \$200,000 towards the fit out of the Centre through multiple fundraising projects (The Advocate 2015a).

Three Letters to the Editor of the local newspaper were noted during this period that referred directly to the policy subsystem and made statements of belief or value. One focused on the urgency required in building the Centre:

It's time the public wrote to the politicians and the local paper insisting this centre be built as a matter of urgency. More than enough lives have been lost because of the unnecessary delays. (Campbell 2013).

One discussed burden of travel and suggested the health profession was opposed to the Centre because of a loss of potential earnings:

Recently, Dr (name withheld) from Hobart whinged about money being spent on a radiation accelerator being tendered for the North West Cancer Centre. To me it seemed as though the doctor would lose patients now forced to travel either to Launceston or Hobart for treatment, and thus would have a reduced income. If Dr (name withheld) had to travel to the North-West Coast each day to conduct a surgery he may then realise the impost put on cancer sufferers to travel to intrastate locations some on a daily basis. (Campbell 2014)

One expressed their view that political issues were delivered 'behind the scenes' rather than publicly:

As we all know, many major beneficial issues are achieved and delivered behind the scenes without fanfare, and are not always deliberately highlighted by the media. (Dudman 2015a)

One North West resident interviewed by a local newspaper stated that coordination of care and consistency of doctors were her main requirements, as well as the option to receive treatment via her local GP to minimise travel.

'What you want is to have some continuity of care. To have the same doctor for pre-treatment also see me post-treatment, and to follow-up so they know

what is going on. 'Instead I saw one doctor and he left; then another one left; and now there's none.' At one point, because of the doctor changes, Mrs Poke's treatment was not organised as it should have been. She said she would ask her GP if she would take on her post-cancer care so she does not have to travel. (Bingham 2015b)

Elected representatives and health bodies also reflected the general view of the community in statements. A North Western MLC commented that the North West community felt frustration and disappointment over delays in the Centre's funding being finalised, and expressed a view that the community had been 'strung along' with promises of services that failed to eventuate.

The north-west residents have been kept dangling on a string by this government with repeated promises and being strung along with promises that have been as hollow as hollow. The north-west community have been told time and time again, 'Yes, you'll get this service after the other ducks are in the row'. All of those ducks are in the row. We were told it would be originally 2012 and then 2013 at that last public meeting in Burnie. People were disappointed by 2013, they thought that was too far away and yet again we are being told it is possibly 2015, 2016, 2017 or who knows. We are tired of being promised the world and given nothing. (Tasmania 2011)

The MLC's views are consistent with community views captured as part of the preliminary review of Tasmania's health system in 2012. The Commission heard evidence at public hearings that the community believed outcomes of health reviews were simply 'shelved' when they proved too difficult to implement and that a level of cynicism in regard to meaningful change had developed.

Previous reviews noted some cynicism from the community with regard to the review process in general. Concern was expressed that outcomes would be 'put on the shelf and forgotten', with no substantial change occurring. (Commission on Delivery of Health Services in Tasmania 2012b, 19)

The Commission also noted that there was an apparent disconnect between public expectations and the level of access that could be offered by specialists in Tasmania, indicating again that community expectations were not necessarily aligned with the structure of the health system.

#### *Media (n=4)*

Statements made by the media continued to be consistently in favour of a regional cancer centre, and articulated a view that community action on the issue had been strong. An editorial in *The Advocate* stated that the community ‘almost to a man, woman and child’ lobbied for a centre to be built in Burnie while key community advocate groups, such as the Cancer Council Tasmania, supported a Launceston based service with improved transport and accommodation (The Advocate 2015b). The same article suggested that statistics on critical mass had been used to dissuade the community and reverse a sense of parochialism but implied that the statistic had been born out of a need to protect the Launceston service, which would see reduced demand under a Burnie-based service.

The cancer centre fight is an example of how the politics and lobbyists with vested interests can stack the argument. Politicians did not expect everyone in the region almost to a man, woman and child to back up time and again and refuse to budge from a collective demand to have the cancer centre built in Burnie...Each time cancer statistics were sought the figures showed the North-West did not factor high enough and this was used to back claims the region expected too much to have a cancer centre in Burnie. That it wasn't safe because of the critical mass factor and Coasters were told to stop being parochial. Of course it was not highlighted how much Launceston required North-West cancer patients as it lobbied to get another linear accelerator instead of the machine going to Burnie where projected cancer patient figures showed it was totally justified by 2016. (Bingham 2014b, 10)

In summary, the period of 2010-2015 was defined by considerable discussion among the media and community in regard to the construction of the North West Regional Cancer Centre. The change in Tasmanian governments in 2014 resulted in a shift in focus for health

service direction in the state and much comment focused on where the credit lay for the delivery of a local radiation therapy service.

### *Nov 2015 onwards*

The North West Regional Cancer Centre commenced operation in late 2015, with radiation therapy starting in mid 2016. This period was marked by very little discussion in regard to the Centre, given that the debate about its existence was now largely resolved. There were no comments or statements found that related to health professionals. The majority of statements came from the media or the community via the media and focused largely on credit for the Centre and the likely effects on the North West population from the proposed One Health System changes. The key themes did not reflect those of the previous periods, instead focusing on budget cuts, productivity, local provision of services versus centralisation, credit for the building of the Centre, oversupply of regional services, and travel as a positive aspect in cancer treatment (see Table 19).

**Table 19**      **19 Evidence of beliefs by major actors, Nov 2015 onwards**

<i>Beliefs</i>	<i>Federal n=1</i>	<i>State n=1</i>	<i>Health Prof n=0</i>	<i>Community n=3</i>	<i>Media n=2</i>
<i>Coordination</i>					
<i>Support</i>					
<i>Travel and Transport</i>				✓	
<i>Safety and sustainability</i>					
<i>Centralisation versus maintenance</i>					✓
<i>MDC</i>					
<i>Equity and access</i>		✓		✓	✓
<i>Politically driven change</i>					✓
<i>Staff skills</i>					
<i>Duplication</i>					
<i>Recruitment and retention</i>					
<i>Health budget</i>	✓				
<i>Community expectations</i>				✓	
<i>Urgency</i>					

### *Federal health policy actors (n=1)*

One document highlighted statements at a federal level, with a Letter to the Editor from a Labor candidate for the federal seat of Braddon. In the letter, the candidate categorised the Centre as 'a long time coming' and placed credit for its funding with the former federal Labor government (Keay 2015, 42). The candidate went on to highlight possible threats to the future of health services in the North West if the \$50 billion of budget cuts proposed nationally proceeded and linked health services to the capacity for society to be productive.

### *State health policy actors (n=1)*

One document was located containing statements by state government members or health bureaucrats. In a news article, the Manager of the new Northern Integrated Cancer Service, and the previous Manager of the Launceston Holman Clinic, stated that 'we need the equipment where the patients are' and indicated that the third linear accelerator in Launceston would be decommissioned as a result in the change in patient distribution between the services (Bingham 2015a, 5). This contrasted with statements made in the 2007-2010 period that a linear accelerator could not be commissioned until safe and sustainable staffing could be assured, indicating a possible change in focus or priority (Speers 2010).

### *Community and community advocates (n=3)*

The entirety of the documents found expressing community views on the policy subsystem were six Letters to the Editor of a local newspaper. The view of the community members was diverse. One writer placed credit for the opening of the Centre entirely with the state Liberal government, elected in 2014:

As far as political will is concerned in respect to the cancer services in Burnie, we are now witnessing the positive political will of the Liberal government opening the facilities in Burnie-something the previous government failed to do. (Shacklock 2016)

Another placed credit with the former federal Labor government:

Thanks need to go firstly to former MHR Sid Sidebottom, who secured \$26 million to build the centre from Julia Gillard's government, and then to all those involved in the building and staffing of the centre, as well as the media and other supporters. (Campbell 2015)

Two assigned credit to the philanthropic donation of a North West businessman:

Acknowledgment of one huge point-but for Dale B. Elphinstone's entrepreneurial motivation skills the cancer centre would not be at the stage it is now-almost there, so appreciation where appreciations due I think. (Dudman 2015b)

This is to say nothing of the fact that the centre was brought about, not by political will from either major party but rather from many years of public pressure and the largesse of Burnie businessman, Dale Elphinstone. (Lee 2016)

One writer made the statement that there was a difference between 'complaining and lobbying' and expressed a view that complaining had been evident among some members of the community and that this had been ineffective in achieving change (Dudman 2015b).

A further writer expressed a view that travel was not an issue for them as a patient and that utilising the Cancer Council Transport 2 Treatment bus had in fact aided their recovery:

It's fashionable, it seems, to write letters full of complaints, but I'd like to write about what happened to me. Diagnosed with cancer, the option presented itself to go by bus to the Holman Clinic at the Launceston General. The bus is named 'the cancer bus', which is a misnomer, as chances are you feel better being in the company of similarly afflicted patients...No, it certainly helps and is speeding up your recovery. (Boyenga 2016)

One final letter provided almost direct opposition to the prevailing community viewpoint. In it, the writer stated that Tasmanians had access to 'a frequency of hospitals and services in regional areas that mainland residents could only dream of' and that 'this is what



Tasmanians don't seem to acknowledge when they complain about services in rural areas'.  
(Anon 2015, 20)

### *Media (n=2)*

Two media articles discussed the policy subsystem after the opening of the Centre in late 2015. However, the focus of these articles moved on to the proposed changes under the One Health System reforms. In an editorial, it was claimed that the state Health Minister had effectively divided the state into 'north and south', without regard for the needs of the North West or recognition of its highly decentralised population (The Advocate 2016). The article outlined concerns that this north/south focus would result in services shifted away from the North West and accused the state government of having ignored evidence of the need for cancer services in the North West in the past in order to bolster support for the Launceston service.

The cancer centre in Burnie provides a good example of what can happen when decisions for North-West patients get made by the crunchers in Launceston and Hobart who see health services from the comfort of cities. Projected cancer patient numbers fully justified the linear accelerator in Burnie. However Launceston was set on expanding its linac services and was not in favour of it. We were told it would be impossible to staff the Burnie cancer service.

The article assigned credit for the building of the Centre to 'relentless' community campaigning and believes this campaigning forced focus on the issue by the state government and prevented the issue of safety from being used to deny a North West radiation therapy service.

If not for the community digging its heels in and campaigning relentlessly to get the cancer centre it would not have been built. Only then the focus was switched to how to make it work in Burnie rather than claiming it would deliver an unsafe service.

These statements were supported by a further article in the same paper, which stated that 'poor decision making' by politicians had been used to ignore evidence of the need for

cancer services in the North West (Bingham 2016). This article stated that equitable access to decent healthcare was the most important matter there was, indicating a deep core value.

Nothing is more important than having equitable access to decent healthcare when you need it...You only have to look at the example of the Burnie cancer service which the region fought for.

## Summary

For the purposes of rigour, the data presented above has been amalgamated to demonstrate the consistency of beliefs from a different perspective, by each actor group across all four periods (see Table 20). This allows each group and its expressed beliefs to be examined in its entirety and in contrast to other groups, which tests the robustness of the data and allows consistency of beliefs across longer periods to be represented clearly. It also allows the more commonly held beliefs, as well as the periods of more belief-related activity, to be represented visually. The table lists all beliefs and all four periods. Each group is represented by its first letter: F for Federal Health Policy Actors, S for State Health Policy Actors, H for Health Professionals, C for Community and Community Advocates, and M for Media.

The data on the beliefs of FHPA demonstrates that there was no belief consistently demonstrated across three or more periods. When the issue of radiation therapy began to have traction in 2007, when the first funding commitment for a linear accelerator for the North was made, discussion focused on Safety and Sustainability as well as Community Expectations, the only two beliefs to be discussed in more than one period. These dissipated after the opening of the Centre in late 2015.

**Table 20 Key beliefs by actors and time period**

Belief	Level	Pre 2007	2007-10	2010-15	2015/16
Coordination of care	PC	F, H, C	S	S, H	
Support	SA	F, C	S	H, M	
Travel, Transport and Accommodation (as a solution)	PC	H	F, S, H, C	S, H	
Travel, Transport and Accommodation (as a burden)	PC	M	C	C	C
Safety and sustainability	DC	S, H	F, S, H	F, S	
Centralisation versus maintenance of services	SA	H, C			M
Multidisciplinary Care (MDC)	SA	H	S		
Equity and access	DC	F, S, H	C	C	S, C, M
Politically-driven change	PC			H, C	M
Staff skills	SA	F		S, M	
Duplication of services	SA	S		H	
Recruitment and retention of staff	SA	S, H	S, H	S, H, M	
Health budgets	SA	S	F	H	F
Community expectations	PC		F, C, M	F, S, C, M	C
Urgency of the issue	PC		S	C	

**Note:** F = Federal Health Policy Actors

S = State Health Policy Actors

H = Health Professionals

C = Community and Community Advocates

M = Media

DC = Deep Core

PC = Policy Core

SA = Secondary Aspects

The data relating to State Health Policy Actors shows a more consistent and developed set of beliefs discussed, perhaps attributable to the local nature of the issue. Safety and Sustainability and Recruitment and Retention were demonstrated across three consecutive periods, with Transport and Travel becoming another focal point as the debate over extended cancer services and the best design for delivering this progressed. These beliefs centre on a practical consideration of administration and resources, in keeping with the nature of this actor group.

The discussion by Health Professionals demonstrated two key beliefs – Travel and Transport and Safety and Sustainability. Travel and Transport was discussed from the perspective of this being a solution to the issue of accessibility for regional and remote patients. The group also repeatedly discussed Recruitment and Retention during the 2010-2015 period after the Centre became a funding reality. This shows a similar focus to that of the State Health Policy Actors, being resource and administration issues.

The Community and Community Advocates groups had three core beliefs, demonstrated across three consecutive periods. These focused on Travel and Transport, Equity and Access and Community Expectations. These represented a focus on individuals and their experience of accessing cancer services, rather than resources or administrative matters. Travel and Transport was discussed from the perspective of this as a burden for patients, rather than as a solution to accessibility.

The Media group had the least consistently demonstrated beliefs, with only one belief – Community Expectations –discussed in two consecutive periods. However, during the period of 2007-2015 the media were at time prolific in generating articles relating to the issue of cancer services in the North West. Their focus on Community Expectations is in line with the perceived role of the media as representing the views of the readership.

The data examined from documents pertaining to extending cancer services in North West Tasmania shows that there was no single belief that was consistently demonstrated across all four periods by any group. This could be explained by a loss of momentum after the Centre opened in late 2015 or a change in focus when the One Health System reforms were

introduced into the Tasmanian health subsystem. However, there were several instances of a belief expressed in three consecutive periods:

#### State Health Policy Actors

- Safety and sustainability – Periods 1-3
- Recruitment and retention – Periods 1-3

#### Health Professionals

- Travel and transport– Periods 1-3
- Safety and sustainability – Periods 1-3

#### Community and Community Advocates

- Travel and transport – Periods 2-4
- Community expectations – Periods 2-4
- Equity and access – Periods 2-4

Overall, the discussion of Travel and Transport was split into two viewpoints. For Health Professionals and State Health Policy Actors it was discussed from the perspective of overcoming issues associated with travel by reinforcing and improving transport and accommodation assistance. From the perspective of the Community and Community Advocates, it was viewed as the burden of travel.

It is also pertinent to consider that at the end of Period 3 the state government changed from ALP to Liberal. Therefore any change in sentiments expressed could be related to a change in ruling party.

This provides preliminary evidence of a possible Coalition constituting State Health Policy Actors (prior to the change in government in 2014) and the Health Profession as the belief relating to safety and sustainability is shared consistently across a period of more than a decade and both sides expressed caution in delivering radiation therapy services to the North West. This requires further analysis (see Chapter 6 Discussion). However, there is no immediate indication of a competing coalition, particularly through the expressed views of

the Media or Community and Community Advocates, who advocated consistently for an expanded regional service and came together in non-trivial action based on policy beliefs. There are numerous statements made in media articles that the community lobbied continuously for an extended cancer service but there is no evidence of it that could be found through document analysis. Actions and beliefs are the evidence of a coalition and there is insufficient evidence in document analysis alone to confirm this.

In order to confirm the presence of a State Health Policy Actors/Health Profession coalition, and to seek further evidence of a possible Community/Media coalition, interviews with stakeholders, patients and patient families are analysed and beliefs ascribed value (see Chapter 5 Results II). This provides another data source in order to test the applicability of the ACF to this case study and its hypotheses.

# Chapter 5: Results II – Interviews

## Introduction

The previous chapter provided a comprehensive document analysis to identify possible coalitions in the debate over radiation therapy services in North West Tasmania, with indication of one formal coalition emerging. This chapter presents an analysis of data obtained from semi-structured interviews to test the hypothesis that the debate around a local radiation therapy service in North West Tasmania during the period 2000-2017 was born out of politically motivated change rather than a formally organised community lobbying effort. It adds to the evidence base created through documentary analysis in Chapter 4. This evidence is presented through analysis of the beliefs evident among the stakeholder group of interview participants, then the patient and family group. Excerpts from these interviews are used to illustrate these beliefs.

Initial expectations were that there would be a coalition that was 'for' a local radiation therapy service in the North West region, most likely consumers, and one against the establishment of more localised specialist medical services. The ACF would also suggest that the government could serve as the traditional 'policy broker' – a third actor whose role is to broker compromise between different policy positions (Jenkins-Smith & Sabatier 1994). However, documentary analysis provided no basis for this belief that consumers and community advocates formed a formal second coalition. It did, however provided some basis upon which to confirm one coalition comprising of medical and health professionals with some overlap with government and health bureaucracy.

In order to further test the application of the ACF to this case study and to confirm or refute the existence of two or more formal advocacy coalitions, interviews were conducted with those involved in or affected by the policy subsystem. These interviews fell into two distinct categories – interviews with stakeholders, those working in or advocating for the design and delivery of cancer services in the North West; and those patients or direct family members from the North West who had accessed such cancer services. The stakeholder group was

further broken down into three subgroups: the policy community, community or community advocates, and health professionals. These participants came from three distinct backgrounds with different perspectives and involvements in the debate.

All stakeholder participants were given a four number code beginning with '00' while patient and family participants were given the prefix '11'. This allowed the two types of interview to be distinguished. Each set of interviews began at 16 rather than 1 so the participant was not aware that they were the first to be interviewed (as the participant number was spoken at the start of the audio recording) as it was considered possible that being first might impact on their responses. When more than one person was interviewed in the same sitting participants were given the suffix A or B, depending on who spoke first, to distinguish participant's responses. Two interviews – Participants 0024 and 0026 – were 'off the record' informal discussions and therefore not included in the analysis of results and no quotes are provided. Two additional interviews involving patients with a family member present resulted in minimal input from the other party – Participants 1119b and 1124b – and as such no quotes were provided from these. Some interviews were shorter than others and thus fewer quotes were provided from these.

The policy community comprised of four participants who had a direct role in policy development and/or implementation via the government and health bureaucracy. Community and community advocates comprised of five participants who were focused on representing the needs of the community. Health professionals came from a health background with a focus on patients, diagnosis, treatment and overall health objectives. There were four participants in this group.

Using the same method as applied in the documentary analysis the beliefs expressed in these interviews were ascribed a value – Deep Core (DC), Policy Core (PC), and Secondary Aspects (SA) (See Appendix 2) – based on the classifications outlined in Sabatier (1988). Key beliefs were determined based on whether something was stated as a fact or an opinion, whether there was repetition and therefore salience of certain words or concepts, and whether identifiers, such as 'I believe' or 'I think' were used. The coding included both the beliefs of the interviewee and what they perceived to be the beliefs of others. As the interviews represented a single moment in time rather than analysis over a 16-year period



the results were presented by group then belief rather than time periods then group, as was the case in Chapter 4. Reference to any person's name was removed and replaced with (name withheld).

## Stakeholders

Stakeholders were recruited from the following areas: medical professionals, elected representatives (past and present), community advocates and health bureaucrats. No media representative could be found to consent to be interviewed. No current serving member of state or federal government agreed to a formal interview, although one current member of Parliament was interviewed who was not a member of the government. Therefore the five groups reported in Results I Documentary Analysis – the federal government, state government, Health Professionals, Media and Community and Community Advocates – could not be replicated in this chapter. Instead, interviews were grouped as follows:

1. Policy Community (n=4)
  - Elected Representatives (n=2)
  - Health Bureaucrats (n=2)
2. Community or Community Advocates (n=5)
  - Employees of NGO (n=2)
  - Community Advocate (n=1)
  - Community Representative on Committees (n=2)
3. Health Professionals (n=4)
  - Oncology Specialists (n=3)
  - GP (n=1)

As the interviews represented a single point in time results were not grouped by any discrete period.

### Policy Community

The policy community comprised of four stakeholders, consisting of two health bureaucrats, one former federal elected representative and one sitting state elected representative. This

group was termed the 'policy community' because of their involvement in creating and implementing health policy through their roles.

This group reflected five consistent beliefs: Community Expectations; Safety and Sustainability; Politically Driven Change; Recruitment and Retention; and Travel and Transport. All four stakeholders expressed all five beliefs.

### *Community expectations*

Community expectations (a PC level belief) were discussed in terms of policy change brought about by a desire within the community to have a local radiation therapy service. However, community expectations were considered to be out of step with practicality and sustainability by some.

When you come to specialised expertise services it is not in the population's best interests to for example, and this is a bit of a throwaway line, have an MRI on every street corner. And the reason for that is there is not sufficient throughput to maintain competency and that is dangerous. – Participant 0019

I've been accused of killing people, had blood on my hands because I wouldn't provide or couldn't provide or whatever the services. – Participant 0022

However, others discussed it in terms of the community working to fundraise and lobby to achieve change.

And we've got some great benefactors in this region as we've already mentioned that have been willing to invest in providing a level of financial support to health services. That's basically shamed governments into it I think. – Participant 0021

We had people who have donated money here, which has actually changed the overall base of everything... that raised the bar for all the machines in the state in because that became the gold standard for the state. – Participant 0020

This belief was therefore consistently demonstrated but was held from two opposing points of view – one supporting community expectations and the other seeing community expectations as unrealistic to some degree.

### *Safety and sustainability*

Community Expectations (a DC belief) overlapped at times with the discussion of Safety and Sustainability. This belief was expressed in the context of any service needing to be safe and sustainable, both economically and from a staffing perspective, in order to be viable. All four stakeholders discussed this belief.

But you cannot expect specialists and high-end services to be competently delivered or reasonably delivered outside of major metropolitan areas. It's about safety. – Participant 0019

The cancer instance in Tasmania is increasing because of an ageing population but it hasn't gotten to the level where it would sustain 4 linear accelerators in the north of the state, it will only sustain just under three. So one of the machines in Launceston will close down and the one in Burnie will open. – Participant 0020

But my view on this is that whatever service we put in place it must be the best service we can possibly have. It's no good having a service that doesn't really meet the medical or health needs of the patients. Sometimes it's better to organise transport to a big facility if that's what's necessary to get top rate treatment. – Participant 0021

The average punter doesn't understand the sophistication or the level of sophistication of the equipment and the services that are required to work efficiently and safely. – Participant 0022

There were some comments made that indicated that the concept of Safety and Sustainability was not mutually exclusive to the proposal to have a radiation therapy service in the North West.

My issue was what is the safest and the best way of supporting people with cancer and their families, and progressively I got more and more – how can I say – acquiescence from the clinical view that we could do it here. –

Participant 0022

Because we joined the two units together we get that a lot more cost-effective by having a networked system across both sites, that makes it more flexible for us to work. – Participant 0020

This belief was therefore also consistently demonstrated and all stakeholders discussed concern about the need for safety and sustainability. However, there was some indication that this could be achieved in the North West if the right model of delivery was found and support was provided from the major players involved.

### *Travel and transport*

Travel and Transport (a PC belief) was another belief discussed by all four stakeholders in this group and represented views about the need for patients to travel out of the region to access services and the role that appropriate transport and accommodation services might play in mitigating the negative impacts associated with this. Viewpoints moved along a spectrum from travel not being an issue for Tasmanians:

I actually don't think that distance in Tasmania is a critical issue...the very small distances that we need to travel in Tasmania pale into insignificance. –

Participant 0019

So many of the people I know with that say, 'Well, if Launceston's the best place that's where we should be going. If it's Melbourne, that's where we should be going or Hobart'. – Participant 0022

So if they do have to travel it's about policy decisions making it easier for them to stay overnight and their support person. So it's about equity of access not equality of access. – Participant 0021

To travel being an impost on those with cancer:

But the things that make patients feel really sick, you know the side-effects are such that they feel terrible, they are the ones who you should really provide as close as you can to their home. There is nothing worse than having to get in a car and travel up when you feel like you might want to vomit all the way home. – Participant 0021

To patients foregoing treatment because of the impost of travel:

So there's people who make those decisions (to have surgery instead of radiation therapy) because of the distance and by having a centre in Burnie those distance barriers access barriers are lessened. – Participant 0020

I know there are people down there in Circular Head who sometimes decide it's too hard to go and have the follow-up mammography after breast cancer and a mastectomy or whatever and they don't. – Participant 0021

If you can't get transport and you can't get accommodation for a longer-term stay for your family, then some people give up, it's just too hard. – Participant 0022

This discussion demonstrates that even within a participant's own response there was some inconsistency about whether travel was a burden or a necessity, highlighting the complexity of this issue. Participants acknowledged that travel could be perceived by some in the community as a burden however all acknowledged that travel and accommodation support was necessary to mitigate this.

### *Recruitment and retention*

Recruitment and Retention (an SA belief) was similarly discussed by all four stakeholders and incorporated issues with attracting and retaining specialist staff needed to run a cancer centre in the North West. All acknowledged that recruitment could be an issue in North West Tasmania.

Who will actually want to go to a regional area where they will most likely only be doing your basic routine type radiation treatment, which becomes very humdrum after a while. It doesn't challenge them, it doesn't provide

them with any professional fulfilment. They get frustrated and angry and they are off. – Participant 0019

Our recruitment relies on getting people here to see the place. – Participant 0020

Unless you can attract really well skilled people and experienced staff and have the latest sort of equipment and that sort of thing that's constantly reviewed and updated then you end up providing a second rate service and the outcomes are not as good. – Participant 0021

One of the arguments I got about the North West Coast is we would not attract the right people to provide the services. I don't mean morally, I just mean you could offer them a bundle of money, but you're also asking them to come to an area where there's a different lifestyle for them, there was a lack of collegiality. – Participant 0022

However there was some divergence as to whether it remained an issue for the North West Regional Cancer Centre.

So in relation to the radiation therapy we had five positions and in the current climate we had 40 odd applicants. So five years ago if you had a position you might have had two applicants or sometimes one. – Participant 0020

So it needs to be part of a statewide service. And in being part of a statewide service means you can be supported, like if you lose a key member of staff. – Participant 0021

There was also discussion of whether past staffing arrangements had been adequate or successful, feeding in to a belief around continuity of care:

(name withheld) was offered the opportunity to work for the cancer centre but she was working for Peter McCallum...She actually did e-health clinics to the patients back here, so she was dedicated ... So she is a very special player in that regard and well loved. – Participant 0020

The discussion of Recruitment and Retention indicates that there is consistent concern over the capacity for the region to attract and retain specialist staff. However, there is indication that integrating the North and North West cancer services may mitigate that issue and evidence that recruitment has not posed an issue for the new Centre in the initial stages of recruitment.

### *Politically driven change*

The most prolifically discussed belief was whether the funding and establishment of the Centre had been driven by political motives rather than clinical need (representing a PC belief). Three stakeholders mentioned directly the idea that policy change was brought about by a populist view.

I think that more and more that policy decisions are being influenced or impacted by populist views. I think that obviously politicians are impacted by this and there is a very strong lobbying network to secure services for the north-west coast... the politicians who want to keep their constituents happy, but happy does not necessarily equal best possible outcome. – Participant 0019

It was a populist thing because there was a lot of people in this region, everyone in this region pretty much knew someone who had to travel. – Participant 0021

Now, whether that (the establishment of the Centre) was driven by good health policy or public demand and/or political pressure is a very interesting debate. – Participant 0022

Three stakeholders also discussed the divide between federal and state health responsibilities and the push by the federal government to instigate or facilitate policy change. The view of the state-employed health bureaucrats was that the state was required to acquiesce once federal funding was committed. The view of the former federal elected representative was that the federal government achieved policy change because the state government didn't want to, indicating credit was attributed along patriotic lines.

It was driven locally and primarily by federal politicians. And so the state's Department of Health developed a submission because they were required to do so and that submission secured funding. – Participant 0019

The Commonwealth said that 'We wouldn't give you the funding to build it unless you manage it and operate it'... (name withheld). She was instrumental in actually increasing that funding envelope because the Commonwealth wanted to reduce it significantly and she manage to fight to get back up a lot. – Participant 0020

On the political level the state government of both persuasions tended to remain somewhat mute about increasing the provision of services on the North West coast. As it reached the federal level, where there was greater funding propensity, I got more and more acquiescence to the idea that we could provide some services, so it became political. – Participant 0022

The consistent and extensive discussion of politically driven change indicates that this was a main driving force behind the establishment of the Centre, rather than simply the result of clinical need or community expectation.

### Community and Community Advocates

The group Community and Community Advocates comprised of one community member who had lobbied directly for the provision of radiation therapy services in the North West via a petition and community forum; two employees of a non-government organisation whose purpose is to support patients and family members affected by cancer; and two community members who had served as community representatives on reference groups providing advice on radiation therapy services in the region. Four key beliefs were expressed within this group: Community Expectations; Safety and Sustainability; Politically Driven Change; and Travel and Transport. All five stakeholders expressed three of these beliefs and four stakeholders expressed one of them.



## *Community expectations*

All stakeholders expressed 'Community Expectations'. It was discussed within this group from the perspective of the community having pressured government to achieve a local radiation therapy service. Three stakeholders viewed this as a positive pressure and positive outcome, with one stakeholder viewing this in a negative way and one in a neutral way. Terms such as 'snowballed', 'passion', being 'strong enough', 'success', 'getting behind it' and figuring out how to 'jump the hurdles' were used to describe community expectations and actions.

It was just one of those situations that snowball excessively. I couldn't believe that so many people signed it... It just goes on to show that there are so many people passionate about it. – Participant 0016

There was a lot of groups that were involved in fundraising for the fit-out of the centre and a number of the rooms are named after those groups up there, which is a wonderful tribute to them and the contribution that they've made to the centre. – Participant 0028

Just a good example of that, I think, where a community comes together to find a solution to a problem it's got rather than just spending its time whinging. – Participant 0029

One notable exception was the dissenting voice, an employee of a non-government organisation, who saw community expectations as unrealistic in relation to a local radiation therapy service.

I think they've got it all just quietly. They should feel pretty privileged. I would say they need to continue to support that service and I mean that as in not to be too negative or too vocal about things that might not always seem perfect, you know. – Participant 0017

This is contrasted with the view of another stakeholder, an employee of the same organisation, indicating a lack of consistency from within the one organisation whose role is to represent patient's interests.

And all of a sudden when government realises that community is strong enough to start the ball rolling, and impact in that way, and raise money, and raise funds to deliver the service, then government has to also participate in it. – Participant 0027

However, there was some discrepancy in what constituted community-driven change, with two stakeholders having been representatives on a reference committee. The stakeholders perceived this committee as a representation of community involvement and community pressure. However both stakeholders acknowledged that the state government formed the committee and they were invited to participate by the state Minister for Health.

Q: What did the community actually do that led to Department of Health saying we should set up this group?

A: I'm not sure. – Participant 0029

I was involved in a community reference group... I was invited by the CEO of the hospital at the time, (name withheld). And I think the minister, (name withheld). – Participant 0028

### ***Safety and Sustainability***

All stakeholders expressed this belief. Two expressed this point of view from the perspective of services needing to be sustainable and the North West having issues in relation to this.

I think the issue that we have to think about is not so much access but is the service always going to be of safety and quality...So we should never compromise on safety or quality just because of access. – Participant 0017

It's a shared staff service delivery model across the entire north of the state...that would enable it to be safer and more sustainable. – Participant 0028

One stakeholder saw sustainability as the belief of the state government but not reflective of his own beliefs.

Their (the state government's) argument was to re-establish that (a radiation therapy service) down here in Burnie was significantly expensive and difficult because of the amount of people you would need, and the scale simply wasn't there.- Participant 0029

These views were similar to another stakeholder, who believed the notion of the North West being unable to sustain a radiation therapy service was not true and that this impacted on equity for the region.

I would suggest also that there is a considerable feeling on the North West coast that the north-west coast misses out because we don't have the critical mass to give us those services when in actual fact we do. – Participant 0016

One stakeholder held a dual-perspective view of sustainability. Some comments made related to the inability for the North West to sustain some services because of critical mass and that this acted as a concern to residents of the region.

Some people...don't feel like they have much opportunity to search beyond who they've been referred to, for example...So, we do have to travel to have that happen, but sometimes that's, realistically, a critical mass thing as well.. – Participant 0027

However, other comments seemed to imply that residents of the region were happy to have any access to a service in the region.

I think there might be a, kind of, relative gratitude for having one (a specialist) at all. – Participant 0027

Overall, both comments by this stakeholder indicated that they believed that some services could not be sustainably delivered in the region, irrespective of how this was viewed by the general community.

The belief of 'Safety and Sustainability' seemed to be expressed by Community and Community Advocates in more neutral tones than the Policy Community. The proposal to have a local radiation therapy service in the North West was not viewed as inherently

unsustainable but the need to ensure sustainability was raised. This belief was not consistently expressed across this group, however.

### *Politically driven change*

This belief was the only one to not be expressed by all stakeholders. Four stakeholders made direct statements about the politically driven nature of the policy change that resulted in the establishment of the North West Regional Cancer Centre. Their views varied as to the main driving force behind the politically driven change. Three viewed it as driven by the community:

So, from my view, I would say that almost, it's the government being dragged into participating as a result of the snowballed community awareness. –

Participant 0027

Initially I took a bit of beating from some of the federal politicians because they felt that it (a radiation therapy service) was totally unnecessary, the wrong thing to do with health funding. But that didn't stop me. – Participant 0016

One viewed it as resulting from election cycles and political manoeuvring:

There have been times when politics has overridden really what is in the best interests of the client, and so there have been times when elections have forced particular policies to be enacted, and so because of that we now have a centre and we now have to make that centre work. – Participant 0017

One stakeholder who believed change was driven by the public also held the belief that this change had been actively opposed by both the state health bureaucracy and by the medical profession within Tasmania.

One interesting comment is that a couple of doctors did come to me and say that this is the wrong thing to do. They were quite against having the services in Burnie. – Participant 0016

It is noteworthy, however, that of the three stakeholders who believe change was driven by the community, none could name more than one or two individuals who drove this community-led push, and none could name any formal group or structured effort to lobby for such change.

Once we had the forum there was no actual group that was organised to facilitate or take it forward. It was really picked up by (name withheld) and some of the politicians, local politicians that dragged it forward. – Participant 0016

No, I couldn't give you any specific names, really. I know-as they say, the media were good in making sure it was pushed hard. – Participant 0029

This indicates that the true source of change still cannot be pinpointed specifically or attributed to any formal group or coalition, even by those who were actively involved in advocating for such change to some level. Overall, there is also inconsistency within the Community and Community Advocates group over where the push for policy change came from.

### *Travel and transport*

All stakeholders discussed the issue of travelling to receive cancer treatment and being provided with adequate support in regard to transport and accommodation. However, there was inconsistency both within the group and within the expressed views of individuals as to whether these posed an issue for residents of the North West and whether travel overall for cancer patients was a negative issue.

Three stakeholders expressed concern that travel was a burden for patients from the North West.

I had quite a few dealings with people that had to travel every day five days a week from the West Coast of Tasmania through to Launceston, an extremely long trip, a long day, particularly when people are unwell. – Participant 0016

I think there are people that I speak to that have said they will not travel to Launceston. They just won't. – Participant 0027

I got really, I guess, to know a lot of the young people that were regularly going to these and travelling to the northwest on buses and back. And it was the whole day. – Participant 0029

However, all three stakeholders who expressed concern at patients having to travel also made statements that minimised the issue of travel. One made the statement that residents of the North West are happy to travel for services such as shopping; another indicated that travelling on the Transport 2 Treatment bus was a positive experience for patients; and another indicated that their personal involvement with travelling to receive cancer treatment had not been a burden.

Distance I think is it's something that people on the west coast and north-west coast are not strangers too because we do travel to other areas. Even to shop. – Participant 0016

I think that having the opportunity to travel, say with the transport-to-treatment, is very positive for people, and they have the opportunity to actually be with other people that are going through the same things. So that's good for them. – Participant 0027

And I travelled up and back every day to that, which for me wasn't too bad because I'm pretty fit and healthy then. So I handled that okay, got a little bit weary towards the end, but it wasn't too bad. – Participant 0029

One stakeholder took an opposing view of travel for North West residents.

Look in general I think Tasmanians have it really good, have a really good health system per se and good access to it. So as much as they may have to travel 300 km from Burnie to Hobart if they had to... you know if you were in outback Western Australia or Northern Territory or Queensland you'd be in a much worse situation. – Participant 0017

The fifth stakeholder took a more neutral view of travel, indicating that as long as support services were in place travel could be effectively handled for patients.

Well, so long as they're well supported to be able to travel, so I guess that's where the Patient Assistance Transport Scheme and the provision of

accommodation, they need to be well supported to be able to do that. –

Participant 0028

These responses show a varied view by this group in relation to the issue of travel for patients, as well as some conflicting information in relation to individual's own viewpoints.

## Health Professionals

This group consisted of four medical professionals – three oncology specialists and one General Practitioner from the North West region. Two of the specialists were interviewed together, which may have altered the responses given. No representative of health professionals, such as union spokespersons, could be found to consent to an interview, meaning interviews were conducted from the perspective of that medical professional rather than from the perspective of the profession overall. No nurses could be found to consent to an interview.

All four participants expressed six key beliefs. This may be higher than other groups because of the smaller number of interviews (three interviews of four stakeholders) or because of the higher level of knowledge in the area of cancer services by this group. The six beliefs were Safety and Sustainability: Community Expectations; Funding Priorities; Travel and Transport; Recruitment and Retention; and Politically Driven Change.

### *Safety and sustainability*

All health professionals interviewed shared safety, quality and sustainability concerns. Overall, the health professional community demonstrated concern that safety, quality and sustainability might not have been best served by a local radiation therapy service in North West Tasmania. Strong phrases and words, such as 'appalling', 'crazy' and 'political' were used to describe the service design in the North West region.

I think expecting to have some whizz-bang cancer centre in Burnie is a nonsense... It's appalling because it's money that, well, the care they get is appalling a lot of the time. It's not that they're getting good care, they're just getting care. – Participant 0018A

It's crazy for, again, it comes back to such a small population. It has to be if you want to get excellent care, like the Peter Mac in Melbourne, then you have to centralise that. – Participant 0018B

The concept of a service at any cost isn't acceptable in this day and age. It has to be a service of the right accessibility with the right quality and standards that stand behind it. – Participant 0023

These views show a consistency among this stakeholder group that services need to be delivered in a way that is safe and sustainable and that this might not have been achieved in the North West.

### *Community expectations*

The discussion on Community Expectations focused on a range of issues. Two stakeholders discussed the role of public opinion on resources.

Everyone has an opinion on how they think things should go and I guess the trick for us is that we get caught with a limited amount of resources...and that is influenced by the general public and the way they vote and how much they jump up and down, write a letter to the editor about provision of access to services – Participant 0018B

Whether it was federal or state, it became part of the touchstone of 'this is what the region needs'. – Participant 0023

Two stakeholders discussed the extent of parochialism in Tasmania and the impact of this on health services.

I must admit, I was from outside Tasmania and I didn't appreciate when I first came to Tassie the divides and things here and how destructive..., and the fact that it continues to adversely affect the health system in Tasmania. – Participant 0018A

Yeah, I didn't either, how parochial the North West and the north and the south are. – Participant 0018B



One stakeholder made several statements about how public perception can be impacted by a lack of understanding by the community and skewing of the issue by the media.

We have advocates, whether they be consumers or patients, and as advocates often are, they'll be a single issue, so they just want this or they just want that, perhaps not able to see the bigger picture.

So I think it's important to know that these vulnerable people can be manipulated by the media and by politicians, and although there were one or two very vocal faces and families that were interviewed in the paper, there didn't seem to be that balance where interviews were conducted with people who perhaps had an alternative view, or they weren't published. – Participant 0025

These discussions give an impression of a negative view of community expectations, in that they are unrealistic, unfounded or impacted by the media or government. Overall, this belief is a consistent one.

### ***Funding priorities***

This belief was an amalgam of Health Budgets (an SA belief) (funding for cancer services) and Other Funding Priorities (PC belief) (funding for health services other than cancer). Discussion from two oncology specialists focused on the limitations of health funding and how money spent on a local radiation therapy service in the North West caused a negative impact on cancer services overall.

Trying to fund it or make it happen is so wrong and does such damage to proper provision of cancer services for people. – Participant 0018A

By trying to provide everyone with everything what you do is you make the pot of money smaller, which means that you can't then provide top class or first class service in one centre, you diminish because you're decreasing the amount of funding. – Participant 0018B

The remaining two participants discussed the negative impact the funding for the Centre had on other competing health priorities that may not have had the public support of a local radiation therapy service. Other health priorities were viewed as perhaps more urgent or significant than radiation therapy in the North West.

That (radiation therapy services in the North West) has to be contrasted though with the broader view of how does that fit in the rest of the healthcare spectrum for the region and there is some concern that the decision that's been made doesn't perhaps take into account what else could we have done with, I'm not sure, \$16.9 million...Obviously by talking about that we could be talking about other preventative health things and other less tangible health services that, of course, don't have the emotional argument. – Participant 0023

I think that the discussion that perhaps never came to the public light was, 'That will cost a certain amount that could otherwise have been spent on other health services'. – Participant 0025

The statements show a consistent view within this stakeholder group that funding for the provision of radiation therapy services negatively impacted health services.

### *Politically Driven Change*

All stakeholders acknowledged a political role in the establishment of the Centre in North West Tasmania. Two stakeholders attributed this to the marginal nature of the federal Electorate of Braddon and the disproportionate influence this affords those constituents.

There are many, many places in Australia where people expect to travel for services, it's just that there happens to be a swinging seat up there, and it's appalling actually...I think money has been inappropriately apportioned to different bits of the state, which means that they can't actually provide any proper services anywhere. – Participant 0018A

If you want to build a whizz-bang centre in the north of the state, well then take that pot of money and put it there and everyone will go, 'That's fantastic,...' But the people in Latrobe...have actually disproportionate influence on the health system of the state of Tasmania. – Participant 0018B

Two stakeholders made more moderate statements about the decisions being ‘political’ in nature, with one attributing this to the sensitive nature of health issues.

I think we have seen a fairly political landscape driving some of the design of this... health services of that sort I think were always going to be politicised and probably always will be. They’re very sensitive issues. – Participant 0023

I think that policy has been somewhat influenced by politics because there was this promise to open up radiotherapy services and there wasn't necessarily the money for the human resources. – Participant 0025

This is another consistently demonstrated belief within this stakeholder group, that the decision was in part made for political reasons, with few if any statements made about there being a clinical need for such a service in the North West.

### *Recruitment and retention*

All stakeholders interviewed in this group shared concerns about the capacity to recruit and retain good quality health professionals to staff a radiation therapy service in the North West of Tasmania. It was discussed in terms of a North West service being costly because of staffing issues.

If you elect to put a new linear accelerator in the north-west for provision of radiation because people don’t want to travel two hours and you’ve got no-one to staff it, you’ve spent millions of dollars that you could have spent actually getting those staff to work in Launceston. – Participant 0018B

There’s a worldwide shortage of radiation therapists and physicists, and so we either have to wait a very long time or pay a great deal of money to recruit the appropriate people. – Participant 0025

Another discussed this in terms of recruitment issues leading to an inconsistent patient experience, being treated by different specialists across their cancer journey.

That over my time has clearly been a pretty patchy journey, I don’t think I’d like to try and recall all of the oncologists’ names that we’ve dealt with, but

there's a clear benefit for patients when continuity is achieved. – Participant 0023

Another participant expressed concern about the quality of those specialists who were recruited to the North West region.

It's appalling...there are some high quality staff there, but there are also some very, very average people who end up being employed there who I wouldn't want my family cared by. – Participant 0018A

Another common issue discussed by all participants in this group related to recruitment and retention was the ceasing of the contract with the Peter MacCallum Institute in Melbourne to provide an outreach medical oncology service to the North West. This question was not asked by the interviewer but was raised independently by each participant. Each participant mentioned that the decision to end the contract was a negative one and that the service provided had been of a good quality and stable. This introduced again a belief relating to continuity of care as an extension of the issue of recruitment and retention.

(Name withheld). Now, her contract was not renewed and I think that was purely political. No idea why. She came from the Peter Mac and she was a great service...and some nitwit... thought, 'Oh, we have to have things in Burnie and not having them flown in from the state' ... Now, I've been here for 16 years and she was delivering the best service that was provided during that time. – Participant 0018A

And now we're looking for locums because we can't get anyone. – Participant 0018B

One area I am at odds with, it was the Green Paper, which accused the Burnie Cancer Service as being a failure, and it wasn't...I knew the oncologist who was visiting that area for the last three years...Yes, she was outreach from Melbourne, but was actually delivering a very good range of care and oversight to treatments that were there. That was called a failure and I'm not quite sure why. Nobody ever came and asked the GPs what was the problem. – Participant 0023

The next model that came along was the model of contract services which were actually purchased from the Peter MacCallum Hospital, and that offered a period of stability for about four or five years...Again that came to an abrupt end without a real discussion with the CAG. – Participant 0025

This presents an interesting paradox. All stakeholders note the difficulties associated with trying to recruit and retain specialists to work in the North West. All stakeholders believed the Melbourne-based medical oncologist had been providing a good quality service to the region. Yet the Tasmanian government opted to terminate the contract, in the opinion of this group, despite the fact that the arrangement was meeting the needs of the community and overcoming the issues associated with recruitment and retention.

### *Travel and transport*

The issue of Travel and Transport to treatment services was discussed from a number of different perspectives. Two stakeholders indicated that patients from the North West did not see travel as an impediment and would do so in order to access the required treatment.

So from patients I get the impression that the transport across from the North West to Launceston and things is reasonable and we don't have difficulties when people have needed to come across. – Participant 0018A

...people are of the understanding that while I live in the community where I live and I'll get my primary services there, my second and tertiary services will be provided elsewhere. – Participant 0025

A further stakeholder added to this by indicating that distances travelled to receive treatment in Tasmania were negligible compared to the rest of Australia and that patients who saw travel as a burden were not considering their advantage living in a geographically small state.

But actually, it's not far to travel in Tasmania. People in Queensland or in Western Australia or in South Australia or in New South Wales are used to travelling large distances for the provision of their care. I constantly have

patients say, 'Oh, I've had to travel all the way from Burnie to Launceston'. –

Participant 0018B

One stakeholder did offer empathy for the requirement for patients to travel and indicated that perhaps the motivation to fund a radiation therapy service in the North West was based on this being an easy solution to perceive and implement.

It's a very emotional argument and why shouldn't it be, it's an incredibly difficult time in people's lives and they can see and touch the experience of having to travel five days a week...So that's an easy one to put into a vision and see that well, we can fix this by doing this. – Participant 0023

The same did, however, indicate that some patients in the region might still prefer to travel to receive treatment and that some residents of the North West might see a closer geographic affinity with the North.

That'll be an interesting discussion in what does the person who's sitting in Devonport think when they're being sent to Burnie for their treatment where they probably would think that they'd prefer to travel to Launceston because that's where the real service is. – Participant 0023

This issue presents a less consistent view than other beliefs expressed by this group. However, all do indicate to some extent that travel is not perceived universally as a burden on patients in the North West region and none express strong opposition to the notion of patients travelling to receive specialist care.

### Evidence of a coalition

The result of the interviews with 15 stakeholders from medical, political, health, advocacy and government backgrounds was a clearly defined coalition, comprising of most members of the policy community and health professionals. This coalition comprises political elites who are actively involved in the policy area and play an important role in policy formation and those with a high degree of understanding of the health area and therefore the policy subsystem (Sabatier 1988). There were shared policy values expressed (Safety and Sustainability, Travel and Transport, Politically Driven Change, Recruitment and Retention

and Community Expectations), which were mostly related to DC or PC level beliefs, placing them higher in terms of value and making them less changeable. Actors were able to identify one another consistently, and actions were non-trivial in nature. Although not all stakeholders interviewed formed part of the policy community, most did. Some of those interviewed had a less involved view of the policy subsystem but only two had a viewpoint that overtly contrasted with that of the others. Two of the participants also demonstrated more of an administrative policy role.

These expressed beliefs of Safety and Sustainability, Travel and Transport, Politically Driven Change, Recruitment and Retention and Community Expectations by the policy community were also consistently found via document analysis over a prolonged period of time, and applied to other issues within the Tasmanian health sector as well. This is exemplified by the findings of the Specialist Reference Group in the lead up to the Richardson Review of 2004 (Shannon 2005), where safety, quality and sustainability were expressed as paramount.

Non-trivial actions by the policy community were mostly related to their employment. Those in the medical profession worked directly with cancer patients and facilitated their treatment and travel. They were on clinical advisory groups, strategic planning committees and reference groups, as well as two interviewees having active roles in forming policy at a state and federal level. The federal policy for radiation therapy services in North West Tasmania was initially formed using a centralist view based on the opinions of clinicians, according to a former federal MP. This is a position noted in Coalition Hypothesis 4 of the ACF – that those in an administrative role within a coalition may advocate for a more moderate position than others in the coalition (Jenkins-Smith, Nohrstedt, et al. 2014). However, this position changed when the health professionals' views softened in the face of federal government support for a radiation therapy services in the region. This is in keeping with the notion that coalitions can alter their strategies when faced with short-term constraints and opportunities (Jenkins-Smith, Nohrstedt, et al. 2014), such as the reality for health professionals that securing funding for a less than ideal North West service might be better than securing nothing at all.

With only one coalition clearly identified as a result of analysis of stakeholder interviews, focus now turns to those interviews with patients and family to determine if there is evidence of a competing coalition within this group.

## Patients and Families

The beliefs expressed by the patient group tended to be more focused on the feeling of the individual and their cancer journey, as well as a focus on relationships and personalities. Overall, the four most commonly held beliefs within the patient group were: Travel and Transport; Independence, Assertiveness, Fear and Power; Negative Experiences of the Health Care System; and Personalities and Relationships with Staff. These represented any beliefs expressed by at least a third of the participants. Restricting this to half of participants would only have resulted in one belief. Loosening this to a quarter would have doubled the number of beliefs, thereby diluting their importance. Therefore one third was considered to be an appropriate measure by which to determine the key beliefs of this group.

### Travel and transport

Eight participants from this group mentioned travel and/or transport to treatment as a strongly held belief, making this just over one third of the total participants. Within the patient group there was a diverse range of views and opinions, including beliefs at opposite ends of the spectrum to one another. Some had received treatment in the local area and some had travelled. There was a mix of those who saw travel as a burden, including those who believed travel actually caused some patients to discontinue treatment:

I could not have imagined having to travel from Smithton or even further down the west coast and it would have been an absolute nightmare for them.

– Participant 1118

The people who would go to Peter Mac, they reach a point, as my wife did, where she just said, ‘I’m not going through this anymore...I don’t want any more treatment because it’s just too hard.’ – Participant 1120

And those who did not see it as a burden:



So if I got to Launceston it was easier to drive the extra two hours to be in Hobart because I had a support base there. – Participant 1131

I've heard a lot of people say in the past how difficult it is and I can understand that, but my experience, the way I felt, was I was getting treatment and if it entailed travel, then it entailed travel. I was just grateful that there was treatment available. – Participant 1122

I would take my son anywhere for the best treatment, the treatment that he needs regardless of where you had to travel to. – Participant 1133

There were patients who would forego treatment if they had to travel out of area to receive it:

I would like to say that, if I'd had to go to travel for radiotherapy or anything like that, I wouldn't have had treatment at all...It would have been completely out of the question. – Participant 1118

And those who preferred to travel to receive services as they equated this with a better quality of service:

So the moral of the story is go outside Burnie. – Participant 1119a

I felt safer going to Launceston (than Latrobe). – Participant 1121

Of note, some of those opposed to the concept of travelling to treatment expressed some contradictory views:

I wouldn't even have considered travelling to Launceston five days a week for six weeks.

My husband...I would have been happy taking him to Launceston. – Participant 1118

This indicated that the patient had been 'happy' travel to Launceston to take her husband for treatment but would not have travelled to Launceston for treatment herself as a patient. This same patient also considered Burnie within an appropriate distance to receive treatment but too far to have easily considered accessing a patient support service.

I may have considered Burnie but, at that stage, they didn't have Burnie.

I think that would be a good thing for some of the ladies (a wig service). But then it was in Burnie. There wasn't one here. So I would have had to travel to Burnie for it. – Participant 1118

There were some who supported the idea of travelling to treatment made similarly contradictory statements. One participant spoke highly of the accessibility of services at the Peter MacCallum Centre in Melbourne and the fact that services were bulk-billed. Travel to Melbourne was not seen as an issue. However, when asked how the Tasmanian health system compared to Melbourne in terms of providing them with what they needed, the participant replied:

It did provide me with what I needed except it was in Launceston. –  
Participant 1119A

This indicated that travel to Melbourne, which the patient had chosen to pay for themselves, was considered a convenient distance to travel but travel from the North West to the North of Tasmania for the treatment he chose not to access in Melbourne was somewhat of an impediment.

Table 21 illustrates that those treated in the North West, either in whole or in part, appeared more certain of the need to have a radiation therapy service in the North West. Conversely, those not treated in the North West were less supportive or less certain of the role of the Centre. This group were also more likely to express support for the notion of travelling to receive treatment. Overall, both groups were happy with the treatment received at the location they received it.

**Table 21 Patient and family views on travelling to receive treatment (n=18)**

	Treated in NW Tas f (%)	Support a NW radiation service f (%)	Happy to travel to treatment f (%)
No	11 (61)	Yes = 2 (18) No = 3 (27) Unknown = 6 (55)	Yes = 6 (55) No = 1 (9) Unknown = 4 (36)
Yes	7 (39)	Yes = 4 (57) No = 1 (14) Unknown = 2 (29)	Yes = 1 (14) No = 3 (43) Unknown = 3 (43)

This shows a negative association between receiving treatment locally and a willingness to travel and a positive association between being treated locally and wanting expanded local services. The total figure in the column 'Treated in NW Tas' equalled 18 rather than 23 as it reflected the number of patients rather than the total number of patients and family members interviewed.

### Independence, assertiveness, fear and power

Four separate but interrelated beliefs emerged within the patient group: Fear (DC belief); Assertiveness (DC belief); Power of Doctors (PC belief) and Independence (DC belief). These all centred on a patient's feeling of being in control of the process they were engaged in, whether this be positive or negative, and thereby overlapped. Independence was expressed by nine participants (patients or family members), fear was expressed by five participants, autonomy by five and the power of doctors by three.

There seemed a desire among some patients to retain patient independence and decision-making wherever possible:

I was extremely fortunate that it could be done at the Mersey, which meant that I could take myself to my treatment and return home again. – Participant 1118

I did my own research and decided that the treatments they were going to offer me were all invasive to an extent that I wasn't happy with. – Participant 1127

I said in the end that was your decision to go along with what the oncologist said, the decision was in your hands so stop being angry because it's not going to help you. – Participant 1128

There were also those who demonstrated independence through declining or not seeking out support services that may have existed for them:

No, we had no advocacy on our behalf at all did we, we did it all on our own really. We didn't contact any support groups or anything like that. – Participant 1119A

At one stage there I did panic and think why are they giving us cancer care nurses?... I didn't think that we really needed them because we were able to do most of it ourselves. – Participant 1124A

And the young lady who used to come and shower-and make sure I had a good shower myself and made the bed...and then they sent another lady that only came a few times to do some cleaning once every fortnight, and last week I rang up and cancelled that because I thought I was capable of doing it myself. – Participant 1125

Some discussion moved beyond independence and demonstrated instances of assertiveness:

And I said, 'So, if there's no bed, what's going to happen?' And they said, 'We'll send my wife back to emergency.' And I said, 'No, you won't. Not after our experience there last night.' And consequently we went through a process, where I reckon they hated me because I said,...'Get a doctor down here and let's get that done.' – Participant 1120

The Launceston Clinic, Holman Clinic wanted me to make an appointment with somebody up there... but fortunately because of my knowledge of the local medical industry, I realised that the Burnie Cancer Centre was in

operation... So I rang the staff that I knew in the cancer department and said, 'What's the story?', they said, 'We'll have a locum here and you're welcome to come and see him', at that stage. – Participant 1127

Some patients expressed a fear of the unknown in regard to diagnosis or treatment:

Services had closed down over the Christmas, New Year period. So we were doing the 'oh my God, what's going to happen, how fast is this rotten thing growing', and all the rest. – Participant 1132A

So he took me in and showed me the machine and how the lasers worked, laid it out on the table for the treatment,...But it would have been probably helpful to know that first up so you have less fear of this terrible machine that's doing things to your partner, you know. – Participant 1122

Similarly, there was a sense of confusion and lack of support once treatment had ceased:

I remember sitting on the couch at the end of my radiation thinking well that's finished, what happens now? And feeling a bit at sea. – Participant 1121

You're thinking, well, what happens now? And there's nothing, there's no follow up. – Participant 1133

There were also concerns expressed that there was a power imbalance between the doctor, who held the knowledge, and the patient, who deferred to this knowledge or felt powerless throughout the journey.

I think the journey is very intimidating for a lot of people. And they feel intimidated by medical professionals as well as the gatekeepers of the medical professionals. – Participant 1131

I didn't really ask a lot of questions about exactly what was happening, I just did what I was told. – Participant 1121

I had cancer and then immediately started chemo in Launceston at St Luke's.  
I'm not sure I was given a choice, it was just like oh well, this is what we're  
going to do and this is where we'll do it. – Participant 1119a

This belief shows a mix of views towards the patient's role in their cancer journey. Some were more focused on fear and deferred to medical professionals. Others were more assertive and focused on maintaining control over their journey. This shows a lack of consistency as to how independence and power are approached by patients, perhaps dependent on their personalities, previous experiences with the health care system or their role (patient or family member).

### Negative experiences of the health system

There were a number of negative experiences with the health system patients accessed that were recounted (an SA belief). Many were complaints relating to peripheral issues, such as the colour scheme of the waiting room, the quality of the food or furnishings, and the friendliness of staff. However, some were more significant than that and clearly elicited a strong emotional response when the participants recounted these experiences. Some related instances involving health professionals:

I thought she was going to die, I really did. It was a very bad experience. And they took her down to the theatre in the morning and I waited around her room all day up until six o'clock. I wasn't told anything, I didn't hear anything... ..I raised a big complaint with the Burnie Hospital about one part of my wife's treatment. I put it all in writing, as I was instructed to. And sometime after she died I got a letter telling me that they offered their condolences on her death and they'd looked into the matter and the doctors that had performed very badly had been given further tuition and blah, blah, blah, and it wouldn't happen again... The system's got a crack in it a mile wide. – Participant 1120

And I was going to have chemo but I had to have a stent put in-is that what it's called, a stent in your arm? That's a port; I think that's a stent. But anyway, it went horribly wrong. – Participant 1125

#### Others gave accounts of misdiagnosis or delayed diagnosis:

I just felt really horrible. And I couldn't put my finger on it, I didn't know what was wrong so I went to AandE here in Latrobe and I thought I might've had a clot in my port because I was aching and da, da. Anyway, the young doctor came to examine me, ha, ha didn't lay a finger on me, didn't touch me, didn't nothing... Eventually she came back and she said to me, she was lovely but she said, 'Mrs X' she said, 'I really think you're suffering from a panic attack.'

'Oh, do you?' – Participant 1121

And he was also saying 'I'm so tired Mum, gee I'm tired.' So we ended up taking him up to the hospital who had a look at him and said 'Oh, no, no, he's got intercostal muscle problem,' sent him home... Within a half an hour of being in the ICU he's put on life support, he just deteriorated so quick. –

Participant 1133

#### Others had negative experiences associated with travel and the travel support schemes:

She didn't seem to get the concept that I was able to travel by myself, or was over there travelling, and that as soon as they gave us the appointment time, we would be at the hospital. She couldn't get that through her head. – 1126B

And to try and claim that through the patients' travel assistance scheme...it was the one time in my journey I wanted to reach my hands through the telephone line and grab the guy by the throat and head butt him, right, because, as I said, to him through clenched teeth, 'I wasn't thinking about the forms when I was trying to deal with the enormity of my diagnosis, and all this stuff.' – Participant 1131

Despite these negative experiences all but one of the participants who discussed these experiences expressed a positive view of the system they had experienced and seemed happy simply to have been able to access the treatment they needed. In fact, all but two participants out of the entire patient group expressed a positive overall view of the health system they accessed.

I think they're very good...We're very fortunate. – Participant 1116

As I said, from my perspective it was reasonably positive...The General, the hospital was tremendous. – Participant 1123

Fantastic bunch of people, absolutely brilliant. – Participant 1130

But, I mean, we were lucky. We got a good outcome, anyway, so we're certainly not complaining... Very caring people everywhere, through the whole system. – Participant 1126BandA

I would still say this man that treated (my son) was the best there was and we are just so thankful for that. – Participant 1133

This indicates some contradictory views within participant's own statements, viewing the system in both a negative and positive light. This could be attributable to surviving the cancer experience and feeling a positive view of the system as a consequence, or gratitude to those who treated them. This is exhibited by the statements of Participants 1126B and 1133 who linked their positive experience with their survival. Or it may indicate that negative experiences are not sufficiently negative to outweigh the perceived positives.

### Personalities and relationships with staff

A key belief discussed by the patient group was the need to feel connected in some way to those staff that patients come in contact with as part of their cancer experience (DC belief). There seemed a strong link between positive views of the service they received and the personalities of staff and the strength of relationships they felt they had with their health care professionals. Twelve participants made statements to this effect, making this the single most discussed belief among the patient group. Some expressed 'liking' staff and health care professionals that they encountered during treatment and the importance of this:

I even know the receptionist by her first name. I now know a little bit about her. Receptionist knows all about me, and I know the group of nurses out there very well. So yeah, it's very good to be like that because it's like going to see friends, almost. – Participant 1117



At Peter MacCallum Clinic and I've virtually chosen to go there ever since. So I chose to go to Melbourne. Because I liked the lady in Melbourne, the doctor, the haematologist in Melbourne. – Participant 1119A

Then I think it was (a specialist) that set it up with (-) the oncologist and he's adorable, I'd love to bring him home, really good, he's such a sweet man. – Participant 1128

Others expressed an inability to create positive relationships with staff because of a lack of continuity or poor interactions:

Because the-we've had-I don't know how many we've had-one, two, three, four-five at least since I've been there, that I've seen, and different doctors... Yeah, you can't build a rapport with them. – Participant 1125

When (the specialist) said, 'Would you like to be seen in Launceston now?' I said, 'No, not with staff that have that attitude.' – Participant 1126A

One participant even expressed the belief that good relationships with health care staff was integral to effective treatment because of their understanding of the health care system:

So everything seems to be covered, you know, but it's like I said before, you really need to make a friend of your GP because your GP sorts things out that might not be covered in the hospital. – Participant 1129

The belief relating to personalities and relationships is consistent with other views expressed by the patient group, which all centred on the individual and their thoughts and feelings. The only belief that overlapped with the stakeholder group was that of Travel and Transport, with this group reflecting very diverse views on the impact this had on patients. There was little, if any, focus on funding, service design, recruitment, sustainability or other resource-related aspects. This made the participants in the patient group very different in nature to the stakeholder group.

## Evidence of a Coalition

Initially it was assumed that interviews with patient advocates (from the stakeholder group), and with patients themselves, might produce a coalition of identified actors engaged in non-trivial actions towards achieving a local radiation therapy service in the region. There were beliefs that were consistently shared among a majority of the patient group and were from a DC or PC level, namely Personalities and Relationships with Staff and Independence.

Likewise, some beliefs were either not consistently held (Travel and Transport) or somewhat contradicted (Negative Experiences with the Health System). However, shared beliefs alone do not create an advocacy coalition. Non-trivial action must be demonstrated.

Of the two stakeholders who represented patients or the community in general, and of the 23 patients and family members interviewed, there were no identifiable actors in a cohesive, stable coalition bound by a shared set of policy beliefs. Of the two stakeholders who had involved themselves in advocating for a local radiation therapy service on the North West coast, neither was able to name another person they believed was also involved in such advocacy. Among patients there was less, if any, evidence of non-trivial action that would underpin a formal coalition. No single person interviewed as part of the patient group had been involved in any non-trivial, or even trivial, action towards a local radiation therapy service in the region. Nor did they make reference to any such group that did advocate for expanded services in the North West of Tasmania. Indeed, this group were actually split as to whether they believed the opening of the North West Regional Cancer Centre was a positive. Those treated in the North West were twice as likely to be supportive of a North West radiation therapy service than those who were not (four as opposed to two). One person treated in the North West was opposed to such a service in the North West. But the numbers who were unsure were nearly half the overall number (eight out of eighteen). This indicates perhaps a high level of disconnection from the issue and therefore the policy subsystem as uncertainty indicates a lack of involvement and certainly a lack of evidence supporting a formal advocacy coalition.

## Summary

Table 22 (see below), through its summary of the key beliefs expressed by both the stakeholder group and patient group, demonstrates that each group had a very disparate set of values. No single belief was strongly expressed by both groups. The only exception appeared to be Travel and Transport, however this belief itself was broken into two meanings. While the stakeholder group perceived travel and transport as a solution to access issues if properly supported, the patient group had mixed views about the burden or travel as opposed to travel overcoming inaccessibility.

**Table 22 Key Beliefs of stakeholders and patients/family**

Beliefs	Level of Belief	Stakeholders (n=15)	Patients/Family (n=23)
		f (%)	f (%)
<b>Safety and sustainability</b>	DC	6 (40)	2 (8.7)
<b>Recruitment and retention of staff</b>	SA	9 (60)	0 (0)
<b>Communication</b>	DC	5 (33)	3 (13)
<b>Equity</b>	DC	4 (26.7)	0 (0)
<b>Continuity of care</b>	PC	3 (20)	0 (0)
<b>Health literacy</b>	PC	3 (20)	0 (0)
<b>Travel, transport</b>	PC	11 (73.3)	8 (34.8)
<b>Power of doctors</b>	PC	1 (6.7)	3 (13)
<b>Politically driven change</b>	PC	11 (73.3)	0 (0)
<b>Other funding priorities</b>	PC	3 (20)	0 (0)
<b>Centralisation</b>	SA	6 (40)	1 (4.3)
<b>Community expectations</b>	PC	8 (53.5)	0 (0)
<b>Media</b>	DC	3 (20)	0 (0)
<b>Support services-formal</b>	SA	1 (6.7)	6 (26.1)
<b>Independence</b>	DC	0 (0)	9 (39.1)
<b>Misdiagnosis</b>	SA	0 (0)	5 (21.7)
<b>Incorrect, or lack of information</b>	SA	0 (0)	5 (21.7)
<b>Negative experiences with health system</b>	SA	0 (0)	7 (30.4)
<b>Family support</b>	DC	1 (6.7)	4 (17.4)
<b>Health budgets, resources</b>	SA	4 (26.7)	1 (4.3)
<b>Skill of doctors</b>	SA	1 (6.7)	2 (8.7)
<b>Personalities, relationships with staff</b>	DC	0 (0)	12 (52.2)
<b>Assertiveness</b>	DC	0 (0)	5 (21.7)
<b>Fear</b>	DC	1 (6.7)	5 (21.7)

(DC – Deep Core, PC – Policy Core, SA – Secondary Aspects)

The beliefs do demonstrate an obvious divide between the foci of each group. While the stakeholder group holds beliefs centred on resources, sustainability, and politics, the patient group holds beliefs that focus more on the individual, feelings and experiences.

The focus of each group was not the only divide noted in the analysis of the interviews. Consistency and action were also different. The stakeholder group bore evidence of a health and policy coalition that was supported further by the findings of the documentary analysis. This coalition had consistently expressed beliefs over a longer time period and actions resulting from these beliefs were non-trivial in nature. The patient group, in contrast, demonstrated no non-trivial actions, no collective behaviour, no participation in the policy debate and some degree of inconsistency in the beliefs expressed both between participants and within their own statements. Beliefs were also largely unrelated to whether a radiation therapy service should have been established in the North West of Tasmania, relating instead to general experiences within the health system. Opinion within this group about the Centre was also divided, with a majority expressing no opinion on its value to the community and only six participants vocally supportive of it.

This lack of consistent beliefs and consistent action further supported the findings of the documentary analysis that no second coalition was obvious within the policy subsystem. Discussion of the explanations for no second coalition, and the explanations for policy change in the face of no second coalition, are required to further clarify these findings.

# Chapter 6: Discussion

## Introduction

The aim of this research was to determine the motivation for the public policy change that resulted in the establishment of radiation therapy services in North West Tasmania. Key to answering this question was understanding what drives policy change and how this occurs. The Results Chapters I and II discussed this research aim through the analysis of documents and through patient and stakeholder interviews and provided preliminary evidence of the possible make-up of actors involved in the debate over radiation therapy services in the North West and the drivers of policy change.

This chapter discusses the significance of the findings. With only one coalition identified through the document analysis and interviews, this chapter discusses the possible explanations for this single coalition subsystem. These explanations include quiescent subsystems; a community coalition of weak coordination; a community coalition of auxiliary actors and policy entrepreneurs; or factors other than a formal coalition acting as a competing force in the subsystem.

The likely impetus for change that resulted in the establishment of a radiation therapy service in light of the absence of a second coalition is also examined. Impetus could have included the force of epidemiological data highlighting a need for this service; by a political strategy to win votes in a marginal seat; or in response to a coalition of community leaders. These are also considered in conjunction with the concepts of bounded rationality and localism, which are evident in the case of a local radiation therapy service in North West Tasmania (West et al. 2017).

The chapter then examines the four conceptual paths to policy change, as proposed by the ACF, and determines the likelihood of each in this case study. These paths include external shocks, internal events, negotiated agreement and policy learning.

The consistency of the findings of this research are then compared with other applications of the ACF as discussed in the Literature Review and the significance of the findings is discussed in terms of its application to the development of the ACF.

## Summary of Findings

### Document Analysis

Examination of relevant documents found evidence of one possible coalition, herein referred to as the Health & Policy Coalition. This coalition constituted state health policy actors and health professionals, with a shared policy belief of issues related to ‘safety & sustainability’. Some overlap also existed for ‘recruitment & retention’ as well as ‘travel & transport (as a solution)’. This group showed a consistent set of shared beliefs across a period of a decade or more as well as evidence of non-trivial action. This action included media statements, proposed health reforms and policy decisions impacting on the health system. This included such examples as the decision to place the third linear accelerator promised for the Northern half of Tasmania in Launceston because of a lack of existing infrastructure and resources in the North West, a decision that was supported by the health professionals community.

The Community and Community Advocates group (one that would have been considered most likely to advocate for policy change to introduce radiation therapy into the North West region) also demonstrated a consistent set of beliefs across a period of a decade or more. These were on ‘travel & transport (as a burden)’, ‘equity & access’ and ‘community expectations’. However, evidence of a formal coalition was absent because of a lack of non-trivial actions engaged in by clearly identifiable actors. Beyond a petition, a community forum and a limited number of letters to the Editor of the local newspaper, there was an absence of any other action on behalf of such a group.

Federal health policy actors and the media overall lacked a consistent set of beliefs over a decade or more and could not be seen to have engaged in any formally organised, non-trivial action over the same period of time. One media representative, however, was quite prolific during the period of 2007-2015, but the period of time required to demonstrate a stable

coalition was not met and any clear links to other like-minded coalition members was not demonstrated.

Were a single petition, public forum and sporadic media articles enough to overcome the previously insurmountable financial constraints identified with developing a radiation therapy service from scratch? Document analysis alone did not provide answers to this question and therefore could not be used in isolation to identify the relevant coalitions in this policy subsystem and their ascribed beliefs. Indeed, beliefs proved problematic to identify through document analysis alone. Core beliefs generally refer to a position relating to more than one policy area (Jenkins-Smith & Sabatier 1993). However, public statements from key actors tend to only relate to the health policy sphere and extrapolating deep core beliefs becomes difficult. What document analysis showed us of the imputed policy beliefs of the major actors was that the medical profession had consistently opposed a local radiation therapy service in the region on the basis of sustainability and proposed a policy of continued outreach services and patient travel. Political representatives, however, had a less consistent policy position. In 2007 radiation therapy could not be introduced in the North West without 'a lot more investment' (Australia 2010, 2437) but by 2010 a total of \$33 million had been promised. The policy position of the community was less certain still, with no clearly defined lobby group from which to impute values.

To fully understand this issue and fill in gaps in evidence, discussion of the interviews with key stakeholders and community members was required to include data from primary sources that were not represented in document analysis alone (Crouch & McKenzie 2006). If the ACF is built around methodological individualism (Cairney & Weible 2015), interviews provided the opportunity to ascertain the level of interest from the community in this issue and the role played by any individuals, as well as gauging the views of stakeholders, including health service bureaucrats. In combination with document analysis, a fuller understanding of this policy change could be achieved to determine the motivation behind the provision of radiation therapy services in North West Tasmania.



## Interviews

The ACF is premised upon two or more coalitions who compete to achieve policy objectives and are comprised of identifiable actors. However, the case of radiation therapy services in North West Tasmania identified only one clearly recognisable coalition via document analysis. Examination of the stakeholder and patient interviews also gave weight to this conclusion of a single coalition. Once again, a health and policy coalition was evidenced in the interview transcripts and demonstrated five shared beliefs: 'safety & sustainability', 'travel & transport', 'politically driven change', 'recruitment & retention' and 'community expectations'. Three of these ('safety & sustainability', 'travel & transport', and 'recruitment & retention') were shared with the health and policy coalition identified through document analysis. The two additional beliefs of 'politically driven change' and 'community expectations' may be as a result of the more personal nature of interviews and the discussion of personal viewpoints.

However a community coalition was not identified. No transcript referred to any collective action by the community or community advocates for a radiation therapy service. No participant made any reference to a lobby group. No non-trivial action was identified beyond the efforts of a single individual (the petition and forum). Some beliefs were shared among a majority of patients ('personalities & relationships with staff' and 'independence') but these were not drawn into an identified coalition. Interviews with patients and family members tended to focus on personal experiences, relationships and personalities of those involved in the health system and issues relating to comfort, fear and independence. The machinations of the health policy process or the political manoeuvrings that shaped them were not discussed to any notable extent. This was consistent with a previous study from the 1990's that found the coping methods of cancer patients tended to be grouped into 'seeking information', 'sharing concerns', 'expressing feelings', 'participating in own recovery', 'requesting support', and 'communicating with health care professionals' (Kruse 1993). These coping methods aligned closely with the expressed beliefs of the patient group and therefore showed a high degree of consistency over time among general patient groups.

The notion of a single coalition subsystem is not entirely new in applications of the ACF to various policy areas. In a 2017 review of 161 applications of the ACF, it was found that 22 of

these only identified single coalitions, with a further 18 identifying no coalitions (Pierce et al. 2017). This was a significant increase from a 2009 review that found only 1% of applications citing a single coalition (Weible, Sabatier & McQueen 2009). However, some of these discuss single coalitions but make mention of 'opposition' to these coalitions, indicating that second coalitions did or may have existed but simply weren't the focus of those studies (Kwon 2007; Parsell, Fitzpatrick & Busch-Geertsema 2014). Quiescent subsystems (single coalition subsystems) are discussed in areas of same-sex marriage (Hughes 2016), abortion (Grießler & Hadolt 2006) and tobacco regulation (Farquharson 2003). In each of these examples dominant coalitions prevailed in quiescent subsystems for long periods of time, while opposition remained disorganised, under-resourced or otherwise fragmented. It was only as a result of a change in scientific information, external shocks to the subsystem, or opposition resources that quiescent subsystems changed to become subsystems with competing coalitions. Kershaw et al. (2017) differ in that they discuss a recent example of a single coalition subsystem, rather than one that was challenged decades ago. In their discussion of the social determinants of health in Canada, the authors highlighted how a lack of an organised competing coalition meant the policy objectives of that group were unable to be achieved. This is in complete contrast to radiation therapy services, however, where the only formal coalition did not stave off policy change that undermined its policy objectives.

## Explanations of a Single Coalition

There are several possibilities to explain the absence of a second coalition that warrant examination.

*First*, Sabatier made reference to single coalitions existing in quiescent subsystems (1988). Quiescence indicates inactivity or dormancy in the debate. However, both media coverage and comments from a number of participants indicate that there was considerable activity in the lead up to the 2010 federal election. The level of public and political interest in the issue at that time indicates that there was active debate and lobbying to change the status quo, albeit by a small number of individuals over a short time period. Therefore this heightened activity does not fit with the environment of dormancy considered conducive to a single coalition subsystem.

*Second*, the community coalition (as it is referred to herein) could have been typified by weak coordination, as outlined by Jenkins-Smith et al. (2014). Additionally, Weible & Ingold defined weak coordination as ‘activities that are in sync toward achieving a common goal but are not jointly agreed upon’ (2018, 334). Stronger versus weaker coordination is meant to account for different levels of action among coalition actors, and indeed there was one stakeholder who took a high degree of direct action towards achieving a local radiation therapy service. However, a lack of any action on the part of the patient group is even less than ‘weak coordination’. No patient identified any instance of action taking to support or oppose a local radiation therapy service. One stakeholder took direct action to support it. A coalition would be expected to have some overarching banner that connects them all and action would be coordinated in some way, be it weak or strong. This group showed no connection or coordination at all. Initial signs of a coordinated group, such as the shortlived FaceBook group calling for a local radiation therapy service, might well have formed into a formal advocacy coalition had their activities been consistent and coordinated over a prolonged period of time (Weible & Ingold 2018). However, such shortlived groups are more ‘coalitions of convenience’. These types of coalitions are not considered advocacy coalitions but rather a group that only form to respond to a specific issue (such as a local cancer service) for a short period of time in order to drive the debate in a particular direction (Weible & Ingold 2018). This gives weight to the notion that there are integrated and non-integrated actors in a policy subsystem – those who engage strongly with the process and those who do not engage (Jenkins-Smith, Nohrstedt, et al. 2014), with the patient group fitting this definition of non-integrated actors. There may have been or continues to be many people who are interested in a particular policy subsystem, but a coalition is considered to demonstrate a higher degree of action than mere interest.

*Third*, it could be that the community coalition comprised more of central actors, known as policy entrepreneurs, and auxiliary actors, an interested but largely disengaged public. Weible & Ingold (2018) discuss the notion of less central, more auxiliary actors and their role within a coalition. An auxiliary affiliate is one whose participation varies over time due to less time or knowledge than others, and may even be a ‘one-shot’ participant, entering the debate for a short period and thereby influencing the process as a result. This is consistent with auxiliary actors such as the FaceBook group or members of the general public who

attended the public forum that was held or wrote letters to the Editor of the local newspaper. Indeed Weible & Ingold (2018) refer to the general public as 'soldiers' who contribute to the cause when called upon by their leader. This is consistent with Weible & Ingold's discussion of the latent-actor approach to coalition formation, where not all actors are mobilized all the time.

However, Weible & Ingold also state that there are three principles that apply to the roles that actors can play within a coalition (2018). These are 'build your network, learn deep and broad knowledge on the topic, and stay involved for extended periods of time' (Weible et al. cited in Weible & Ingold 2018, 339). These three principles do not seem to be demonstrated by the collection of individual advocates, auxiliary actors and the general public in the instance of a local radiation therapy service in NW Tasmania. No network was built that can be identified through data collection or direct discussion with the advocates involved. There is no evidence of any coordinated attempt to build deep and broad knowledge on the topic, with none of the few advocates for the service coming from a cancer services background nor demonstrating a development of knowledge in this area after becoming involved. And, most importantly, there is no evidence that they stay involved for extended periods of time. Only one person, the local journalist, showed evidence of extended involvement. Even the advocate who facilitated the forum and designed the petition had no further involvement beyond a single year. Therefore this case study is not consistent with Weible & Ingold's statement that a coalition can be defined by central and auxiliary actors who stay involved for prolonged periods of time. Further, the question needs to be posed in regards to how many central actors or leaders a coalition needs in ratio to auxiliary members for it to be considered a coalition. This case study demonstrated only one advocate involved for a short period of time and one journalist involved for a longer period of time. If the general public are mobilized at the request of their leader then who was the leader in this instance? If the journalist was considered a leader were they aware of this role? Is it possible to have a coalition that comprises of only one central actor engaged for an extended period, one advocate who was not associated with the journalist in any way and considered there to be no coordination between the two, and no other actors except for latent actors and members of the general public? Can a coalition really be two unrelated actors and the general public?

A different way of perceiving the role of an individual who takes on a strategic role within a policy debate is as a policy entrepreneur. The policy entrepreneur is acknowledged as a change agent in the ACF and several other theories on policy change (Mintrom, Salisbury & Luetjens 2014). They are the 'champion of ideas' and 'are strategic in mobilizing support for their ideas' (Weible & Ingold 2018, 332). These actors can be either individuals or groups who promote certain policy solutions by increasing the appeal of a particular idea. The policy entrepreneur has been increasingly integrated into discussion of the ACF when considering the impetus for policy change when one coalition appears either absent or less organised and engaged in the policy process. Policy entrepreneurs challenge the status quo by building a groundswell of support and a body evidence for the need for change. Beland and Cox (2016) purport that a policy entrepreneur will take an idea with broad-ranging appeal, such as a local radiation therapy service in the local community, and use this as a magnet to draw a coalition in around the idea. This appeal is increased in three ways: by manipulating the idea to redefine a policy problem so that it seems more necessary for policy change; by ensuring the idea is embraced by those actors key to the policy process; and by bringing together actors who might previously have been at odds or actors who did not have a specific policy preference until the idea was framed in a manner that appealed to them (Beland & Cox 2016). The strategic framing and management of the issue by the policy entrepreneur can mobilise the support needed for change and bring together a range of actors who might otherwise have been disengaged from the debate. Ideas that are polysemic and carry a stronger emotive meaning are more likely to appeal to a broader audience and thereby generate stronger support.

Such a description fits with the case in question. It may explain why the idea of radiation therapy in North West Tasmania had no clear lobby group behind it and no groundswell of support until it was presented as an election issue through the petition and public forum. One stakeholder interviewed, participant 0016, was instrumental in promoting radiotherapy services in the region as an issue of regional importance. One journalist framed the issue as one of significant community desirability. This position challenged the status quo, as exemplified by the public statements of the AMA (2010c). The idea was broad in its meaning and its appeal. To some, the policy change was about travel, to others it represented regional development, and to others it was about equality between regions. To many it also

represented the fear attached to cancer, which gave the issue its strong emotional valence. This allowed the issue to carry broad appeal and to generate a clear policy preference in the minds of a community that had up to then been disengaged.

The issue of radiation therapy was in competition with other policy proposals at the time, however, from other areas within health and from external subsystems. Policy options are most heavily debated during election campaigns and therefore policy entrepreneurs must overcome competing priorities by building support for the idea and generating evidence that leads to a momentum for change (Mintrom, Salisbury & Luetjens 2014). In this case, support was built via the petition to state Parliament and the public forum in August 2010. The Clinical Expert Panel Report, which came after the initial commitment to fund the service, confirmed the viability of such a service and therefore provided the evidence that was needed to finalise the model for service delivery (North West Radiotherapy Clinical Expert Panel 2011). Several stakeholders interviewed concurred that this radiation therapy service came at the subsequent expense of other equally important health issues, such as cardiology and respiratory services (Participants 0023 and 0025).

It is feasible that coalitions will comprise of some actors who take on a more overt, leadership role, and auxiliary members, such as members of the community. However, the problem remains that under the ACF the basic definition of a coalition once again implies that there be clearly identifiable actors brought together by non-trivial action. Auxiliary members must still be identifiable as members. Interest alone, or even signing a petition, does not equate to non-trivial action and therefore, despite the presence of policy entrepreneurs in this case study, a second coalition still cannot be identified.

A *fourth* explanation for the lack of a second coalition could be that it is something other than a local community/regional coalition. Actors promoting a local radiation therapy service in the region might come from somewhere other than the region itself, perhaps a coalition of politicians or a political party attempting to advance the issue. One participant, a former federal MP, did state that the reason why radiation therapy services came to the North West of Tasmania was because of intervention by the then-federal Health Minister and Prime Minister. They could not identify a community coalition but could pinpoint the people within politics who had pushed to fund the cancer centre. However, as the federal member, they

had originally attempted to form a policy based on a more centralist view (one that did not include radiation therapy in the North West) because of the lack of support from clinicians for a local radiation therapy service and in keeping with the view of their party. The MP subsequently changed focus when it became clear that the federal government would fund the service.

Additionally, the federal government had earmarked funding for a third linear accelerator in the Northern half of the state in 2007 but the funding went to Launceston in the North rather than the North West (Australia 2010). A true coalition would comprise actors with a high degree of consensus in their policy beliefs over a prolonged period attempting to affect an outcome to achieve those objectives. This would not have involved funding a linear accelerator elsewhere if their policy beliefs centred around a local radiation therapy service in the North West, and would not have involved a key actor changing the focus of their policy on a radiation therapy service (from centralist to pro-radiation therapy). The funding commitment from the federal government may have enabled the building of the Centre, but there was no evidence that an identified coalition of politicians actively sought to bring about this change in policy over a prolonged period. Also, as stated by Weible & Ingold (2018), an advocacy coalition and a political party are different types of groups. While political parties are formal entities with membership and a shared, broad ideology that spans across multiple policy issues, an advocacy coalition is more informal, with no formal registration of members and a narrower ideology that relates to the single policy issue under consideration. These reasons combined do not add weight to the idea of a political party of group of politicians representing a second coalition.

Perhaps more likely is that rather than a regional coalition there was instead a sentiment of localism that was simply harnessed as a political tool during an election campaign and rooted in the idea of 'politics of place' (Crowley 2000). Funding for a radiation therapy service could simply have been a tool to build a sense of localism and harness political support rather than an expressed wish formally presented by an organized community to government. This again fits neatly with the concept of policy entrepreneurs, whose role is to frame and reframe issues in order to broaden their appeal and make the case for policy change. This policy entrepreneur or entrepreneurs may have been the federal Health Minister and/or Prime Minister, the major parties in general, local media, local

philanthropists or even the federal member. Driving policy change through enhancing a sense of localism could have achieved a desired policy objective for these change agents and thereby circumvented the formation of an actual pro-services coalition.

## Explanations of Policy Change

### Impetus for Change

With the possible actors, coalitions and shared beliefs identified through document analysis, discussion turns to the role these groups and beliefs played in the policy subsystem and the ultimate policy change to establish a radiation therapy service. The opening of the NWRCC in late 2015 did bring about increased accessibility of radiation therapy services for the North West population. The very introduction of a new service into a region creates enhanced accessibility by virtue of its proximity to the local population. But what were the motivations for change that resulted in this service being created? And at what cost? There are three possible impetuses for policy change that are examined herein in the discussion of the document analysis. These are the force of epidemiological evidence on the need for radiation therapy services in the North West region; a political strategy employed to win public support as part of an election or re-election campaign; and finally, coordinated and effective lobbying for such a change by a coalition that supported the introduction of radiation therapy services. Upon analysis, political strategy was the most likely impetus for change in this instance.

### *Epidemiological evidence*

The ACF's Learning Hypothesis #5 states

Even when the accumulation of technical information does not change the views of the opposing coalition, it can have important impacts on policy— at least in the short run— by altering the views of policy brokers. (Jenkins-Smith, Nohrstedt, et al. 2014, 199-200)

In the examination of the literature, there is little evidence to suggest that policy change was brought about in response to technical information on the need for a radiation therapy



service. The peak representative body of the medical profession, the AMA, was consistently opposed to the introduction of the service because of long-standing issues with recruiting and retaining specialist staff in the region. Similarly, medical organisations demonstrated a lack of evidence existed to warrant a North West service. This opposition was commenced in 2006 when COSA indicated that Tasmania had two radiation therapy services already when a population of 600,000 was normally required to safely sustain one service (Clinical Oncological Society of Australia 2006). Given Tasmania's island status and population of less than 600,000 the need for radiation therapy services was agreed, but the insinuation was that no further service was needed at that time. The AMA began direct opposition to the North West service proposal during the 2010 federal election campaign both before and after funding commitments had been proposed for such a service. One media releases opposed the proposal, then, once funding was commitment, the tone changed to 'cautious welcoming', then back to opposition (2010a, 2010b, 2010c). This opposition stayed consistent, even after the Centre had begun its construction (Dolan 2011; Stephens 2014). The AMA repeatedly warned within these media comments that funding was more urgently needed in other areas of health, particularly heart disease, something that was reiterated by medical professionals who were interviewed as part of the stakeholder group (see Chapter 6).

Additionally, mapping of distances travelled to radiation therapy services found that North West Tasmania fared comparably well to other states, indicating that the perception of distance was greater than the reality (Clinical Oncological Society of Australia 2006). This was further supported by another review that excluded Tasmania entirely from its analysis of cancer service delivery models because of Tasmania lacking the level of remoteness experienced by mainland Australia (Adams et al. 2009). This seemingly added weight to the evidence that a North West service was not justified.

The Clinical Expert Panel Report that examined the viability of radiation therapy services in the North West and the possible models for delivery did find that a service in the North West was viable in terms of patient numbers but it found no evidence that travel to Launceston for radiation therapy was unsustainable or onerous beyond the anecdotal (North West Radiotherapy Clinical Expert Panel 2011). Therefore, the view of the medical profession remained that while demand from North West patients would increase, a standalone service

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in the North West was not sustainable and travel to the North was not unreasonable to order to make the best use of specialist staff.

The viability expressed in the Clinical Expert Panel Report could have been seized as technical information that did not sway the view of the opposing health profession's view but did provide policy brokers, the state and/or federal government, with enough credible evidence to move forward with the project. However, the use of this technical information, when the same Report found no under-servicing of the region and no evidence of hardship in the current arrangements, needs to be questioned. Instead, the same report may have provided weight to both sides of the argument and leads the reader to question what constitutes 'technical information' and how it can be used to support or oppose one view or another. Wilson et al (2008) had a similar finding in their discussion of parental views on childhood vaccinations. Technical information was able to be sourced and used by both sides of the policy subsystem, thus reaffirming the policy beliefs of each side through the acceptance of that evidence which reinforced their views and the cognitive filtering of evidence that did not. Each side was able to perceive the evidence that favoured their view as the more credible, thereby making evidence more subjective than objective.

### *Political strategy*

The second question is whether policy change was brought about by political strategy. This is especially pertinent when reflecting on the highly marginal status of the federal Electorate of Braddon in North West Tasmania. This possible motivator can be used in testing one of the hypotheses that underpins the ACF. The ACF's second Policy Change Hypothesis states

The policy core attributes of a government program in a specific jurisdiction will not be significantly revised as long as the subsystem advocacy coalition that instated the program remains in power within that jurisdiction— except when the change is imposed by a hierarchically superior jurisdiction. (Jenkins-Smith, Nohrstedt, et al. 2014, 203-204)

In breaking this hypothesis down it is helpful to start with an analysis of health funding, as this is a major source of hierarchical power. The Constitution notably does not grant any specific powers to the Commonwealth to make decisions in relation to public hospitals

(Scully 2009). Instead, funding such as Specific Purpose Payments can be used by federal governments to influence the policies and action of state governments. This is achieved largely because of the vertical fiscal imbalance created by an inability for states to generate sufficient revenue to fund health services and potentially undermines the notion of federalism (Dalton 2006). One such example of funding provided directly from the federal government to the state government for a specific purpose is the operation of the Mersey Community Hospital in North West Tasmania. The Mersey Community Hospital was a state-owned and -run hospital, but became a federal election issue and was 'taken over' by the federal government (Grube 2010; McCall 2010). Prior to the takeover the *Tasmania's Health Plan* recommended consolidation of high acuity inpatient, intensive care and emergency services to the Burnie campus of the North West Regional Hospital (ANAO). The Mersey Community Hospital would then be utilised for lower acuity patients, day surgery and outpatient clinics. In what was described as a 'policy shocker' and 'throwing money at marginal seats' (Grattan 2007), John Howard announced his intention to directly fund a Community Trust to operate the hospital, which would lease the hospital from the Tasmanian government (Auditor-General 2014). The announcement was made without any consultation with the Labor state government. The AMA responded to this policy as 'destructive and quite stupid' while the Chair of one of the health reform reports (known colloquially as the Richardson Review) reiterated the lack of population base in the North West to sustain two major public hospitals (Grattan 2007).

The Tasmanian government did not agree to the lease but offered to sell the hospital to the Commonwealth. The final purchase price was \$1.10 (GST inclusive) (Auditor-General 2014). The subsequent federal Labor government also chose not to proceed with the Community Trust model and instead ended up engaging the Tasmanian government to resume operation and management of the Hospital under a Heads of Agreement. Under the Heads of Agreement, the Tasmanian government received between \$49 million and \$68 million per annum from 2008 to operate the hospital, with the Agreement ongoing. The Mersey Community Hospital was quarantined from assessment for the distribution of GST and the funding provided to Tasmania under the national health funding arrangements. This meant Tasmania removed the operating costs of one major hospital but kept the same level of health funding.

Further pointing to the political expediency of the decision is the fact that Tony Abbott, as Health Minister, had previously floated the idea of a federal takeover of public hospitals only to have the idea dismissed by Howard because of the possible politically negative consequences (Grattan 2007). So the reintroduction of the idea by Howard himself as part of the Mersey takeover, in light of previous dismissal, can be seen as evidence of political opportunism.

The Mersey takeover can be considered an external shock that resulted in change in that particular subsystem. It also had ramifications for the radiation therapy subsystem. federal intervention during a federal election campaign on an issue of state responsibility, health services, became seen as an accepted practice and as a result a public expectation that federal candidates could and would intervene of issues of regional importance was raised.

Like the Mersey Community Hospital, radiation therapy services were the responsibility of the state government but became a federal election issue. Federal funding was committed during the 2007 election campaign but the state government was then required to apply for the funding and commit further money for the fit-out and ongoing operational costs of the Centre, despite having only installed a third linear accelerator in Launceston a few years prior. This concurs with the findings by Gathje (2009), that federal funding gives a sense of legitimacy to policy proposals that make them difficult to oppose. Therefore, in examination of Policy Change Hypothesis #2, the same state jurisdiction that established the current program of service delivery remained. However policy change, it could be argued, was imposed hierarchically, with the federal government using its advantages in terms of financial resources to force the policy change. This explanation of policy change provides the most likely reason for why radiation therapy services were established in North West Tasmania.

But would this change have occurred without the intervention of the federal government? The evidence here is mixed. On one hand, Braddon was a marginal seat in what was going to be a close election. On the other hand, funding had previously been concentrated on the Launceston service, including the 2007 commitment that led to a third linear accelerator there. Significantly, discussion over the possible funding of radiation therapy services only became noticeable after a petition was presented to state Parliament in 2010 on the eve of

a public forum in the lead up to the election. This indicates that the move from no radiation therapy to a radiation therapy service reached a marked increase in momentum during the federal election campaign of 2010, with no clear timeline from the state government for achieving this change.

### *Lobbying by the community*

The third alternative in the search for an explanation of this process of policy change is that there was effective lobbying by a coalition of community leaders. This brings discussion back to the very definition of a coalition. The ACF is premised on the notion of two or more coalitions that compete for influence in the policy subsystem (Jenkins-Smith, Nohrstedt, et al. 2014). Yet the document analysis shows a poorly defined mix of actors and possible coalitions. Those opposed to radiation therapy services are identified, with the health bodies such as the AMA expressing consistent and clearly articulated views on this issue.

The coalition in support of these services is less clear. There was a petition drafted by a member of the community and presented to state Parliament in 2010. The same person facilitated the public forum on the issue. There were multiple media articles by one journalist but no link between these two individuals. No formal lobby group was identified except for a single reference that was made to a now-defunct FaceBook group in one media article (The Advocate 2010c). Document analysis does not identify any coalition of community leaders, or any other person who is clearly and consistently associated with the push for radiation therapy in the region, despite this policy change being achieved. This does not lend support to the notion that policy change was achieved in response to a coalition of community leaders.

Although only one coalition is readily identifiable, the ACF can still shed light on the process of policy change in the face of 'wicked problems'. One of the assumptions of the ACF is that 'the set of relevant subsystem actors includes any person regularly attempting to influence subsystem affairs' (Jenkins-Smith, Nohrstedt, et al. 2014, 190). The ACF also assumes that 'change in the world is primarily driven by people and not by organizations' (Sabatier 1987, 685). This then leads to the question of whether change was agitated for by something or someone other than a consumer coalition. The concept of active individuals in the guise of

policy entrepreneurs (Beland & Cox 2016; Mintrom, Salisbury & Luetjens 2014) comes back into consideration again. This could have included the individual who drove the petition and forum, or the media (or single journalist), or even key politicians.

### *Bounded rationality*

In addition to the three possible impetuses for change, the impact of bounded rationality on the decision-making of those involved also needs to be considered. While bounded rationality in itself may not have been the impetus for change, it could have impacted on the way in which evidence was viewed and considered during the decision-making process as well as during the analysis of the original issue and its importance to stakeholders and the community.

In his article *The politics of evidence-based policymaking* (2016), Paul Cairney explores why policymakers sometimes make ideological rather than evidence-based decisions. Cairney said

efforts will fail if scientists and other experts fail to understand how the policy process works. To do so requires us to reject two romantic notions: first, that policymakers will ever think like scientists; and second, that there is a clearly identifiable point of decision at which scientists can contribute evidence to make a demonstrable impact.

Cairney goes on to summarise how policymakers only gather a limited amount of information before they make their decisions quickly. These decisions can be made using emotions or gut feelings and pre-determined ways to gather evidence. Cairney also points out that scientists and experts tend to focus more on the *supply* of evidence, i.e. ensuring there is high quality, hierarchically organised evidence that draws strong conclusions, rather than the *demand* for evidence. By this, he meant ensuring evidence is introduced before decision-makers have made up their minds as well as using emotion to draw attention to your point of view.

In this case, acting on the desire to be elected or re-elected, the political parties vying for power in the 2010 federal election gathered enough information to form the basis of a decision, one that could win public support. This decision was that the community desired a

radiation therapy service in the North West and that building a service in that region was the pre-packaged solution that played well on the emotion attached to the issue of cancer. Other alternatives, regardless of how clearly they were articulated or how strongly the 'experts' in the field of cancer services promoted them, could not find traction in the midst of this boundedly rational decision-making. The notion of using emotion to filter and prioritise information fits well with the notion of cancer as an emotive issue. One study found that when emotive issues were involved, such as emergency contraception, it was often hard to achieve policy change in your favour or oppose policy change not in your favour (Schorn 2005). This reinforces the view that evidence on sustainability presented by the health profession was not able to counteract the emotion attached to the issue of cancer and accessibility.

This demonstration of bounded rationality can be highlighted with a few direct quotes drawn from the interviews conducted. One member of a non-government organisation involved in cancer services stated 'there have been times when politics has overridden really what is in the best interests of the client...elections have forced particular policies to be enacted...' (Participant 0017). Another, a senior specialist, stated 'money has been inappropriately apportioned to different bits of the state which means that they can't actually provide any proper service anywhere.' (Participant 0018A)

These comments, and the notion of boundedly-rational decision-making fits with the belief of Politically-Driven Change, which was mentioned across all stakeholder groups, with only one stakeholder not making direct reference to this. The belief that change was made for political reasons gives weight to the idea that decision-making was based on satisficing and reaching an aspirational level.

A recent article explored further the concept of bounded rationality and how it impacts on policymaking (Cairney & Weible 2017). In it, the authors discuss that bounded rationality is not something to be given up but understood and new strategies learned that allow people to better achieve their policy goals with bounded rationality in mind. The authors acknowledge that knowing how people make decisions and engage with the emotion of issues, such as cancer, is only beginning to develop and that theories will only ever part of

that knowledge gap. The policy process will remain complex and those involved in it will continue to adapt strategies to respond to it.

### *Localism/regionalism*

Notions of localism or regionalism could also have equally impacted the decision-making rationale, driven by political opportunism (Dare 2013). This sense of localism has been evidenced by the fact that hospitals in the region have historically operated autonomously and benefitted from a high degree of public support. Attempts to change the mix, or downgrade existing services have been met with strong reactions from the local community. Howard's intervention in the downgrading of services at the Mersey Community Hospital, as discussed above, highlights the political attractiveness of responding to a sense of localism. The community was against any loss of services in their region and Howard wanted to leverage this to ensure his candidate's re-election. Equally, for whatever reason, be it an unidentified community coalition, the representation of community wishes through the media or a boundedly rational view of community desire, the commitment of funding to build a radiation therapy service in North West Tasmania met with equal enthusiasm to feed this sense of localism.

The results of the interviews showed some strong signs of localism among the North West community, even if it wasn't necessarily demonstrated through a formal, active coalition or lobby group. One person heavily involved in lobbying for radiation therapy services stated that there was a considerable feeling on the North West coast that they miss out because they don't have a critical mass (Participant 0016). This person stated that forcing North West residents to travel for radiation treatment was unfair and that a local service needed to be built to deliver equity. That person went on to say 'if people needed to come from Melbourne to Burnie for treatment an hour's flight and back is less than having to go through to Launceston or Hobart. So there is a possibility of expanding the clientele.' In summary, their view was that people from the North West should not be made to travel to Launceston (as little as 50 minutes away) but that people from Victoria could travel to North West Tasmania to receive treatment and that this was OK as it addressed the feelings of inequity among the region's residents.



Another patient expressed their adamant refusal to travel to Launceston to receive radiation therapy, if this had been required (Participant 1118). However, travel to Burnie would have been considered. When it was pointed out to the participant that travel to Launceston was only 10 minutes further than to Burnie, the participant's response was 'Well, I don't know. I'd have to think about that'. The participant went on to describe Burnie as part of their local area and Launceston as belonging to another region, thus displaying a greater affinity with Burnie.

Interestingly, not all the patients interviewed showed a strong sense of localism. Indeed, some were quite vocal in their opposition. One patient stated 'regional parochialism has for want of a better word buggered the hospital system in Tasmania... They've wasted so much money where they could have a damn good helicopter service' (Participant 1127).

The media could also have been considered instrumental in fostering or framing this sense of localism, and the media demonstrated regional attitudes towards the issue. As discussed above, multiple articles appeared in the North West newspaper, outlining the issue of radiation therapy as one of significance to the community. In these articles, the community response was described as one of 'anger' (The Advocate 2010g) and that a lack of radiation therapy services would 'cost lives' (Speers 2010). Alternatively, articles in the national media described attempts to win voter support in North West Tasmania as a 'shocker' that 'will delight many locals' (Grattan 2007). The Southern Tasmanian-based newspaper described anger from Hobart residents over a lack of funding commitments in the South, with the Northern electorate of Bass seen to be benefitting from 2016 pre-election 'pork-barrelling' (Clark 2016). Each region would perceive its own regions needs and inequities and express these through the media to reflect regionalised sentiments.

### Paths to Policy Change

If, as discussed previously, no second coalition existed in the push for radiation therapy services, and if the conditions did not fit the criteria for a single coalition subsystem, how can we account for the substantial policy change that resulted in the building of the North West Regional Cancer Centre and the introduction of radiation therapy to the region? Government programs, such as the delivery of radiation therapy services, are seen as a

translation of the policy core beliefs and major changes, those that change the direction or goals of the subsystem, such as offering radiation therapy where it did not exist before, must result from a trigger of some kind (Jenkins-Smith, Nohrstedt, et al. 2014).

The ACF offers four conceptual paths to policy change, such as that seen in the North West radiation therapy services subsystem. The paths are policy learning, external shocks, internal events, and negotiated agreement (Jenkins-Smith, Nohrstedt, et al. 2014). Policy learning is seen as the enduring alteration of intentions resulting from experience and causes a revision of the beliefs associated with the policy subsystem. This can come about through a better understanding of the issue or new information. Policy learning, however, is thought to lead mostly to changes in the secondary beliefs, rather than policy core beliefs, and will usually only result in minor policy change and incrementally achieved (Jenkins-Smith, Nohrstedt, et al. 2014). This is largely because the individuals involved in the policy subsystem are bounded rationally, meaning they simplify the world through their beliefs and can therefore be prone to assimilating information in a way that is biased towards these beliefs. In this case study there was clearly a major policy change and a fundamental win for the regional community amidst an adversarial policy subsystem (Weible & Sabatier 2009). Although according to one participant, clinicians may have softened their view towards a local radiation therapy service, media statements made by the AMA (Tas) and the views expressed by the medical community during interviews do not support this claim. This does not indicate any level of policy learning by one coalition leading to a policy change.

The second mechanism for change, external (or exogenous) shocks, results from events external to the control of the policy subsystem actors and can increase the likelihood of major policy change by harnessing increased public or media attention. Change is only likely, however, if the external shock is harnessed by a minority coalition. The idea of an external shock seems a possible fit with the case study in question. In 2007, when funding for a third linear accelerator went to the North instead of the North West, the local federal MP stated that the public saw this as a 'broken promise'. This 'broken promise' was an external shock to the subsystem and thus created further discussion around the need for such a service in the region (Australia 2010). Momentum seemed to build from there, with ever-increasing media articles, particularly in the regional newspaper. *The Advocate* had 29 separate articles mentioning access to a local radiation therapy service in the region between 2007-2016 and

used such language as ‘long-awaited funds’, ‘a hot political issue’, ‘community anger’, ‘unforgivable’, ‘government inaction and broken promises’ and ‘a gross inequality of services’ to describe the issue (Bingham 2009b, 2010a; The Advocate 2010c, 2010d, 2010g). There was also the petition and a forum that was held on the eve of the 2010 federal election (Participant 0016) and the now-defunct FaceBook group mentioned in one media article (The Advocate 2010c). These disparate activities culminated in the 2010 election commitment to fund a radiation therapy service from federal funds, which constituted another external shock. However, the harnessing of this shock and momentum by a formal coalition is still unclear. Each person was unconnected to any formal group and was not assisted in their efforts by any other identifiable actors. Once again, the role of the policy entrepreneur could explain the lack of a coalition but the driving force behind policy change.

The third route for change – internal events brought about normally by actors within the subsystem – also holds some possibility in this case study. A local philanthropist donated money towards half the purchase costs of a Magnetic Resonance Imaging (MRI) machine for the North West Regional Hospital as well as funding scholarships for Radiation Therapists for the North West (Bingham 2014b). This involved an internal actor creating a change that was able to sway public belief towards the viability of a local radiation therapy service in the region. This public belief then served to heighten government attention to the possible program changes. Indeed, as one participant stated, the state government had been left hamstrung by the actions of a private citizen when the donation was announced, as it did not include infrastructure and ongoing operational funding. Once again, the actions of an individual, who acted as a change agent through philanthropic donations, can be seen as evidence of a policy entrepreneur effecting broad support for the issue through making the overall funding seem achievable.

The final mechanism of negotiated agreement is premised on collaborative institutions conducive to negotiation. As discussed above, the policy subsystem was adversarial rather than collaborative, with polarised beliefs between the actors, fragmented authority between governments (state and federal) and a clear policy winner and policy loser (Weible & Sabatier 2009). Similarly with policy learning there is no evidence that the policy community actively sought to change their position and instead opt for regional radiation therapy

services. The policy change seems clearly to result more from a victory of localism by harnessing the potential of the 2010 federal election.

Whichever path for policy change is most likely or applicable, the case study highlights that major policy change was effected by intervention on the part of the federal government into a state government responsibility. One participant, a state MP, indicated that the state government had not intended to substantially alter the existing government program, and that radiation therapy services were not on the agenda in the North West for the foreseeable future. Change was only the result of the federal funding commitment in conjunction with a private donation, which seemingly forced the hand of the state government.

While the hierarchically imposed change (a funding commitment by the federal government) is easily identifiable, as well as the possible mechanisms for policy change, the ACF is still not able to be readily applied to an instance with only one identifiable coalition. This creates an opportunity for perhaps broadening or reconsidering the definition of what constitutes a coalition under the ACF in order to better capture such instances where one coalition seems to be involved in a policy debate with a 'Clayton's coalition'. In this particular case there is evidence that when external and internal shocks were experienced, policy entrepreneurs harnessed the opportunities presented by these to broaden support for a policy change. The role of exogenous shocks in shaping policy change is a cornerstone of the ACF and is evidenced in this case. In particular, the instance of hierarchically imposed change is a clear example of an exogenous shock. As True et al (2007) discussed, the forces that can constitute an exogenous shock are often external to the typical policy decision-maker and include elections that often result in a change of decision-maker. Policy entrepreneurs and the media also framed these shocks effectively, in order to create a narrative that better serves the interests of policy change. If funding for the third linear accelerator in 2007 not being given to the North West and the private donations for an MRI and scholarships really were the 'turning point' in this case would these still have been defined as external or internal shocks had it not been for the role of the media and a few individuals in framing them as such, or by a change in policy direction by the federal government? This highlights how it has been the efforts of a few unconnected actors, rather than a second defined coalition, in harnessing shocks and presenting the perception of a high level of interest by

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the general community that has counteracted the concerns of the policy community and achieved policy change.

## Answering the Research Question

‘Why was the policy decision made in regard to the establishment of radiation therapy services and the North West Regional Cancer Centre in 2016?’

The ACF is a comprehensive structure that is applied in policy analysis yet also seeks to explain belief change and policy change, giving it the explanatory and predictive elements of a theory (Sabatier & Weible 2007). It was developed to deal with ‘wicked’ problems – ‘those involving substantial goal conflicts, important technical disputes, and multiple actors from several levels of government’ (Sabatier & Weible 2007, 189). The analysis of the establishment of radiation therapy services in North West Tasmania can be considered a ‘wicked’ problem that is answered, in many parts by the ACF.

But first, it is important to revisit other theories discussed in the literature review to determine how well such theories applied to the case study and, therefore, whether the ACF is the most applicable in answering the research question.

Pluralism was the first theory discussed. The theory prescribes that resources and power are widely distributed and that the state is a neutral decision-making body (Addicott & Ferlie 2007). Decisions are reached through compromise, not conflict. These elements of the pluralist theory do not find traction within the case study of radiation therapy services. The traditionally powerful role of the medical profession, the unequal resources of the federal government as compared to the state government, the influence of the media and the direct involvement of government in influencing the outcome do not appear consistent with this theoretical basis.

Elitism was also discussed, with power not considered to be widely distributed and instead held by the so-called Kingmakers (Maluleke 2010). However, in the case of radiation therapy services it was not the traditional elite – the medical profession (Palmer & Short 2014)– who affected policy formation. The clearest form of power in this instance was found within the media or hierarchically superior levels of government, both of who were advocating for the

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rights of the community. This does not fit well with the elitist view of power and policy making.

Punctuated Equilibrium Theory describes how focusing events can result in significant policy change and that event destabilises the policy environment (O'Neal 2011). While the federal commitments to fund a radiation therapy service in the North West can be seen as a significant policy change and as a focusing event, it is hard to pinpoint what sudden and destabilise event caused the federal government to make such a commitment. There is no clearly defined catalyst that led to the commitment. The commitment itself becomes the catalyst for change, potentially fuelled by the commitment made by a local philanthropist early in 2010, but with no evidence to confirm the donation acted as a catalyst. If what Cairney (2007) states is accurate, an issue will pierce the public conscience enough to move onto the political agenda. But there is little evidence to demonstrate that the issue did pierce the public conscience in any significant way. The issue moved from hardly being mentioned in the media prior to 2010 to being discussed prolifically in the months leading up to the 2010 federal election, with no clear catalyst.

Coalition Structuring was a theory borne out of the ACF and believes that coalitions are only formed once a threat or opportunity is looming, rather than having the typical decade of consistency and stability as prescribed in the ACF (Breton et al. 2008). Indeed, it can be considered plausible that a push for radiation therapy services only really appeared in the lead up to the 2010 federal election when the opportunity to make it an election issue arose. However, the case still lacks a clearly defined coalition, newly formed or otherwise. The Literature Review hypothesised that the sorts of transient coalitions captured by Coalition Structuring may be the latent actors mentioned in the ACF (Sabatier 1988) but there is still little evidence to support the theory that more than a handful of individuals mobilised themselves from latent to active during this period of debate.

The Narrative Policy Framework (NPF) does offer some strong explanatory powers in regard to radiation therapy services, but operates more as an extension of the ACF rather than a framework in its entirety. The NPF looks at how framing of the narrative can contribute to policy change by creating a new normative setting or value prioritisation, even in the absence of scientific facts, by creating a new story (Shanahan, Jones & McBeth 2011). This

appears consistent with the case of radiation therapy services. No new scientific evidence supported its establishment over and above retaining existing services and instead focusing on transport and accommodation for patients. Indeed, the scientific evidence still appeared to suggest that a service in the North West was not sustainable. However, the media used emotive terms to frame the issue, and thus create a sense of inequity between the North West and the other regions. The media used such language as 'long-awaited funds', 'a hot political issue', 'community anger', 'unforgivable', 'government inaction and broken promises' and 'a gross inequality of services' to describe the issue, consistent with the ACF notion of the 'devil shift' (Sabatier, Hunter & McLaughlin 1987) and consistent with the NPF premise that meaning and prioritisation is affected by words and symbols. Even if the prioritisation did not manifest as action on the part of the community it did manifest in the form of action on the part of the federal political parties vying for election in 2010. What cannot be known is the extent to which the framing of the issue and the emotive terms used by the media influenced the decision-makers.

In answering the research question, the ACF has some strong explanatory powers in relation to the establishment of radiation therapy services in North West Tasmania. A subsystem relating to the safe and sustainable delivery of radiation therapy services is evidenced over a period of a decade or more. Actors came together as part of at least one coalition with consistently held policy beliefs and attempted to utilise a variety of resources to exert influence over the policy subsystem. The division of data into discrete beliefs allowed for easier analysis of the possible coalitions, pointing to a strength of the ACF in its focus on beliefs and its clear delineation between what constitutes deep, policy and secondary beliefs. By using language that clearly links statements, viewpoints, and any other expression of what is important to actors in a subsystem to beliefs, and by linking these beliefs to specific levels, the ACF allows a straightforward mechanism for organizing and prioritizing data.

However, in this case study policy change was achieved not by the identified health and policy coalition but by another group, one that is not easily explained using the ACF. It is clear that a mix of external and internal subsystem events relating to the funding of radiation therapy services, both within the North West region and other regions, focused attention on the issue, drawing to a climax during the 2010 federal election campaign. There

is a likely role of the policy entrepreneur in effecting this policy change, with framing of the issue by the media as one of justice, equity and need for the community. Subsequently, hierarchically imposed change was brought down upon the Tasmanian government, as has occurred in previous instances, resulting in a policy change for North West Tasmania. The application of the ACF, however, cannot be complete without further clarity around the absence of a second coalition.

## Contribution to Theory Development

Although the ACF in its current form can be applied to the case study of radiation therapy services in North West Tasmania to answer the research question in parts, the research findings do provide scope for possible development of the ACF and consideration for further explanation of certain aspects of the flowchart.

### Single Coalition Subsystems

The largest contribution this research may make to theory development, in particular regard to the ACF, is the existence of policy change in the absence of a formally recognised second coalition. While findings of single coalitions – be they subsystems where one coalition dominated for a prolonged period of time, or subsystems where only one coalition was the focus of the research – in the application of the ACF are not unique (Weible, Sabatier & McQueen 2009) and indeed are rising (Pierce et al. 2017), instances of single coalition subsystems that fail to achieve their intended policy change are unique. To date, no literature was located that discusses single coalition subsystems where the policy change was made in opposition to the policy beliefs of the coalition that did exist. When we look back at the literature that applied the ACF in Chapter 3 – Literature Review – each analyses discusses the way in which coalitions strengthened their capacity to influence the policy outcomes over another clearly identified coalition. Therefore, logic would suggest that in subsystems with only one coalition that holds the appropriate resources, or only one coalition at all, that coalition would prevail in achieving policy change. This research is unique in its finding that the opposite was achieved and promotes the need for further



development of the ACF to account for such outcomes and perhaps consider more fully the influential and pivotal role of the policy entrepreneurs.

The discussion by Cairney (2007), Breton et al. (2008) and Farquharson (2003) of tobacco regulation divided the debate on tobacco regulation into two predictable coalitions – the pro-tobacco regulation coalition, largely public health advocates, and the tobacco industry. Resources favoured the tobacco industry, and indeed these existed as quiescent subsystems with only one formal coalition, until the strength of scientific evidence eventually turned the force of public opinion in the favour of those seeking regulation and created a formal opposing coalition with sufficient coordination and resources to counter the policy arguments of the tobacco industry. Each side was identifiable and their actions non-trivial and the quiescent subsystem became a multi-coalition subsystem.

Parsell et al. (2014), which like this research is Australian-specific, also focused on a single coalition in the development of a housing strategy to address homelessness called Common Ground. While this study discussed the coordination and success of the coalition in achieving policy change, it did not find definitively that no second coalition existed. Indeed the study instead focused only on one coalition but made mention of opposing views, whether they were formally coordinated or not. This research by Parsell et al., however, is similar to the case study presented in this instance as it found that the Common Ground project had been promoted despite a lack of evidence-base for its likely success and another, more established alternative being available. Yet, like with this study, policy makers and politicians were adamant in their support for the model, almost in a more intuitive manner than a scientifically-supported manner.

The absence of a second coalition in the case study of radiation therapy services in North West Tasmania should lead to questions about the capacity to achieve policy change. Certainly, discussions by Kershaw et al. (2017) highlighted the poor outcomes for those who did not effectively organise themselves to represent their interests, with specific regard to health advocacy for young Canadians. The authors stated that the absence of a formal coalition created a 'void' that meant there was no incentive for governments to change the status quo. And yet the status quo was changed, but only after a formal coalition was

specifically created to address this void. Had the authors of that research not created such a coalition, history would suggest that policy change would not have been achieved.

This leads us to question Coalition Hypothesis #1:

On major controversies within a policy subsystem when policy core beliefs are in dispute, the line-up of allies and opponents tends to be rather stable over periods of a decade or so. (Jenkins-Smith, Nohrstedt, et al. 2014, 195)

The lack of a formally identifiable coalition, as well as the lack of consistently expressed beliefs among the media or community over a period of a decade or more, does not support the hypothesis that each coalition is stable over time. Instead, the results find that those involved in lobbying for policy change were disconnected from one another, opportunistic and short-lived in their timing or trivial in their actions.

This policy change also leads back to the discussion of Change Hypothesis #2:

The policy core attributes of a government program in a specific jurisdiction will not be significantly revised as long as the subsystem advocacy coalition that instated the program remains in power within that jurisdiction— except when the change is imposed by a hierarchically superior jurisdiction. (Jenkins-Smith, Nohrstedt, et al. 2014, 203-204)

There may have been an absent second coalition but in the case of radiation therapy services it did not mean that there was no group or person effecting change. The results have found a possible role in framing the narrative by the media and direct involvement by the federal Health Minister and even Prime Minister. These individuals may have fit the definition of a policy entrepreneur, as discussed above. This research demonstrates its strength through highlighting the need for future research to clarify a clearer role of the policy entrepreneur in policy subsystems in order to understand how they may act as a proxy or substitute for a formal coalition. This is particularly important given the fact that if policy entrepreneurs did manage to effect policy change in this instance, they did this in opposition to the only formally coordinated and identified coalition involved in this subsystem.

## Short-term Constraints and Resources

An additional consideration for the development of the ACF is defining those elements that might be considered as constraints and resources of coalition actors. In the Advocacy Coalition Flowchart (see Figure 4) the long-term coalition opportunity structures are clearly defined and discussed: degree of consensus required; openness of the political system; and overlapping societal cleavages. These were discussed in the Chapter 4: Results I. However, the flowchart does not provide any prescriptive short-term constraints or resources, which has one of two effects: it either serves to have researchers ignore a possibly crucial element of the flowchart through a lack of detail and direction; or it creates an overly-open interpretation of what may constitute constraints and resources.

As discussed in Results I the ACF does define six categories of resources: formal legal authority to make policy decisions; public opinion; information; mobilizing of troops; financial resources; and skilful leadership (Weible et al. 2011). These were discussed in terms of radiation therapy services and the debate over their establishment. Many of these could have been considered 'short-term' or opportunistic in nature. There is scope to incorporate more specific short-term constraints and resources, similar to as those identified, into the flowchart to aid in clarity.

## Other Contributions

This research also demonstrates its strength in the development of the ACF through several other means. Firstly, this research adds to the limited number of Australian studies that have applied the ACF. One analysis of 80 applications of the ACF over a 20-year period found that Australia had been the focus of only 3 such studies (Weible, Sabatier & McQueen 2009). This study has added to the Australian-specific cases of the ACF, along with such studies as Parsell et al. (2014).

It also adds to the growing body of literature applying the ACF specifically to the sphere of health. The same analysis by Weible et al. (2009) found that health had not been the focus of any such studies until 1999 and from there began to steadily increase in application. This increase demonstrates a growing acceptance of the applicability of the ACF to health analysis and this research serves to further this.

This research is further strengthened by its specific and explicit testing of two of the formal hypotheses of the ACF. An analysis had found that 55% of the studies that applied the ACF had not tested any of the framework's hypotheses (Weible et al. 2009). This research, however, drew conclusions in regards to the applicability of one such hypothesis (Policy Change Hypothesis #2), which had only been tested in 8% of studies, confirming that the hypothesis was sound in regards to this particular case study. It also tested another (Policy Change Hypothesis #1) and found it not to be supported by this particular case study. The specific testing of hypothesis serves to improve the development of frameworks and models, as is the very nature of a hypothesis.

## Validity of the Study

External validity can be measured through four types: population; setting; task/stimuli; and societal/temporal changes (University of Nebraska n.d.). When considered in light of the findings of this research, external validity is confirmed across several of these types. Population validity (whether results can be transferred to other groups or the wider population) can be evidenced in policy entrepreneurs (in this case the media) framing issues of local importance in regard to other population groups. To illustrate this, the journalist prolific in discussing the need for a regional radiation therapy service in North West Tasmania then championed maternity services in a similar way. A proposal to amalgamate maternity services from two sites in North West Tasmania to one site under the One Health System reforms has been described by the journalist as a case of the state government stating 'pipe down and take your medicine' (Bingham 2015e); a political decision (Bingham 2015c); and a reform agenda where the North West is the only loser (Bingham 2015f). The spate of articles on maternity services even provided evidence of the 'devil shift' (Sabatier, Hunter & McLaughlin 1987), with the journalist stating that 'the doctor (sic) union gets wheeled out to support what suits doctors best and the fear factor about patient safety is their trump card. Health ministers stand in front of MCH supporters and say things like 'with all due respect' it's for your own safety' (Bingham 2015e). This demonstrates that the findings in this research in regard to the involvement of the media in framing issues as of local importance and using emotive language can be and was applied to other population groups (maternity service users rather than cancer patients).

Setting validity (the extent to which the results can be applied to other locations) is also evidenced in political strategy used to effect policy change. Such evidence was found in the aftermath of the 2010 federal election, when then opposition leader Tony Abbott pledged \$1 billion for the construction of a new Royal Hobart Hospital in order to win support (and thereby form government) from Independent MHR Andrew Wilkie (Karvelas 2010). An attempt was made to change policy relating to the redesign and renovation of the hospital, something that was a local health issue for the people of Southern Tasmania, in order to win political advantage. This provides strength to the findings in this research that political strategy is an impetus for policy change.

This research also adds support to temporal/societal validity of the concept of localism in health policy and reform. Much discussion has been highlighted already that points to a long history of attempts to downgrade, repurpose or alter the mix of health services offered in the North West, each having been met with some degree of resistance from the local community. From attempts to repurpose the Ouse Hospital (Shannon 2010), to the Mersey Community Hospital 'takeover' of 2007 (Grube 2010) and, more recently, proposed changes to maternity services in the North West (Bingham 2017), there is evidence of a continued demonstration of localism in North West Tasmania in regard to health services. This research on radiation therapy services only serves to further reinforce this validity.

## Strengths

External validity is a particular strength demonstrated in the findings, and indeed the design and implementation, of this research. However, there are other elements of this research that provide strength and rigour. The use of two types of data source, one longitudinal and the other primary data, allowed evidence to be confirmed across a range of sources, formats and time periods. The results found via these two sources were also consistent, adding to its validity. Document analysis yielded a large number of results that were relevant and pertinent to the research conducted and represented a broad range of types (see Table 14 in Chapter 5). Likewise, interview response rates were slightly above the initial target, with 30-35 as the initial target and 38 participants (with 2 of these 'off the record') interviewed. These interviews included a good balance of stakeholder groups, as well as a

mix of patients, spouses and parents. This response rate and balance gave a richness to the interviews that allowed better analysis and stronger conclusions to be drawn. The information derived from these interviews was consistent with that from the document analysis, adding further to its validity.

A further strength of the findings discussed in this chapter is the original contribution to the development of the ACF as discussed above. Applying a theoretical framework as a guide to policy analysis is only half the purpose of such research. Taking the opportunity to test its hypotheses, establish its applicability and providing areas where it can be extended, improved or reinterpreted is the measure of effective and original research.

## Limitations

The limitations of this study can be grouped into two focus areas: limitations of study design and procedures and limitations of the underlying theory. Limitations of the research included scope of the research, interpretation, contradictions and conflict, data collection, sample size, and interviewer bias.

## Scope

Limitations can occur when research is restricted to a certain geographical region, specific point in time, limited population sample or a unique set of circumstances. This research was limited by geographical region, looking solely at patients who resided in North West Tasmania at the time of diagnosis. Residents in other parts of the state, or in other states, were not considered. The research also focused on only one diagnosis type – cancer, in its multiple forms. No other diagnoses, diseases or conditions were examined. Therefore the population sample was limited to those with a cancer diagnosis and the services delivered to this population group.

## Interpretation

Analysis of the beliefs expressed across both document analysis and interviews showed repetition and crossover of multiple beliefs between groups. The sorting of the statements made by participants and in documents into beliefs required the subjective interpretation of them by the Doctoral candidate. This can result in the beliefs of the researcher impacting on their interpretation of others beliefs. This was minimised by ensuring consensus among the Doctoral Candidate and the supervisors as to how data was interpreted and sorted.

Despite the same beliefs being expressed by multiple groups, these beliefs were often interpreted in different ways by the participants themselves, which ultimately changed the nature of the belief and thereby the values imputed within them.

The main example of this was the discussion of Travel & Transport. Within the Health and Policy Coalition, as well as some FHPA and even Community and Community Advocates, travel was not perceived as an unnecessary or onerous burden upon patients. Indeed, travelling to treatment services and receiving assistance for transport and accommodation were considered to be the solution to poor accessibility for rural and regional patients. All stakeholders in some form or another mentioned this. Only one stakeholder was not supportive of patient travel and did not discuss the benefit of transport and accommodation assistance.

The patient group tended to discuss Travel & Transport from the viewpoint of travel as a burden, consistent with the view raised by the one dissenting stakeholder. Not all patients saw travel as a burden. Only four of 18 patients were overtly opposed to travelling for treatment while seven were supportive of travel. Significantly, seven patients expressed no viewpoint on travel either way. Also of note was the correlation between treatment in the North West and a higher propensity to perceive travel to treatment as a negative (see Chapter VI).

The tendency to discuss travel from the view of burden within the patient group could be explained by the fact that the experience of travel directly affected them. One article discussed a multitude of literature that found separation from family caused by travel to

treatment could be psychologically distressing and make the experience of cancer more profound for those patients (Payne, Jarrett & Jeffs 2000). The same article did find, however, that on the whole this did not stop patients from accessing the required treatment, contradicting some literature that cited anecdotal evidence of patients not accessing treatment in Tasmania because of travel imposts. Stakeholders were more likely to view travel from the perspective of services to patients as a consumer and that support services, such as the Patient Travel Assistance Scheme, were more likely to feature in their responses.

The outcome of this separate interpretation of the same issue is that the belief can become confused. While Travel & Transport did feature as a shared belief among groups, the different perspectives on this need to be considered before the belief can be understood and the actors attributed to possible coalitions.

## Contradictions and Conflicts

The strength of the results obtained, especially through the interviews with stakeholders and patients, can be limited by evidence of contradictions and possible conflicts or skewed perceptions by these participants. These can undermine the way in which their responses can be perceived, interpreted because of their inconsistencies or possible skew and therefore analysed.

### Positive and Negative Views of the Health System

The first contradiction was statements made by patients and family members that expressed a simultaneously positive and negative view of the health system they had accessed. Among the patient group nearly one third discussed both negative and positive views of the health care system and all but one participant discussed a positive view of the health system overall. Negative views tended to focus on personal experiences with the health system, including misdiagnosis by medical professionals, treatment by inexperienced medical staff, conflicting personalities and a lack of communication with family. Minor negative issues were also noted in relation to food provided by health sites during treatment, colour schemes in waiting rooms, and other such examples. Positive views were largely expressed through statements relating to the professionalism of staff, overall satisfaction with the



health system and personalities. These divergent views by individuals make it more difficult to determine the true reflections they have on their experiences and therefore their true beliefs.

This tendency to have both negative experiences yet an overall positive view of the health care system is not unique. A study conducted in 1999 on client experiences with coordinated care found that what the client might see as important in terms of their experience and their decision-making were often deemed as peripheral by health professionals in terms of health outcomes (Shannon et al. 2000). The authors summarised that the client experience is shaped by access to three resources: basic resources, including access to public health services; intrapersonal resources, including confidence in understanding and decision-making; and interpersonal resources, including satisfaction with communication with health professionals. The results found that most participants felt a high level of basic resource satisfaction. This was because of the fact that access to treatment during a serious diagnosis (a basic resource) increases the patient's satisfaction across all other areas as well. Patients, on the whole, were simply happy to have been able to receive treatment. It did also find that patients with a dedicated care coordinator felt more empowered and involved in decision-making yet did not challenge professional authority or demand better services. This perhaps indicates that patients feel that empower is important but still do not use it to control their own health decisions, meaning that intrapersonal and interpersonal resources are more about the idea of empowerment than the exercise of it.

The same study also looked specifically at the expectations of rural and regional patients. The study noted that rural patients felt a level of frustration at not being able to get the services they needed in their local areas but at the same time rural patients were more likely to feel self-sufficient and their expectations led them to believe that they would cope with their distance and access issues (Shannon et al. 2000). This is consistent with the results of an article published in 2013 that found rural cancer patients expressed a higher level of satisfaction than their urban counterparts because of expectations (Miedema, Easley & Robinson 2013). More limited access to services caused rural patients to believe they were receiving the best possible care when they accessed it. This is consistent with the views expressed by many of the patients and family, being high satisfaction with the care they were able to access. Yet, there were still several patients who expressed strong

dissatisfaction at not being able to access services in their local area, rather than a sense of self-sufficiency, although this number was in the minority.

### Positive and Negative Views of Travel

The results also indicated that there were inconsistencies in some participants' own views towards travel. The concept of travel is central to discussions of accessibility and featured heavily in the comments of many patients and family members. However, these inconsistencies made the true beliefs of patients less certain when they were seemed contradicted.

One participant had been happy to travel from North West Tasmania to Launceston in the North in order to facilitate her husband's treatment but not her own. This could be understood through the changing role from carer to patient and the impact of her own illness on her willingness or capacity to travel. However, her perceived willingness to travel to Burnie in a hypothetical situation of receiving radiation therapy was contradicted by her reluctance to access a cancer patient support service as it had only travelled to Burnie and not closer to her home town. Another participant paid voluntarily to receive some services in Melbourne while also accessing others within Tasmania. The travel to Melbourne was not perceived as an issue but the travel from North West to Northern Tasmania was seen as somewhat of an inconvenience. This raises the question of whether the perception of distance changed with the level of service. Potentially life-saving radiation therapy may have provoked a stronger willingness to travel than a wig service. Likewise, the choice to travel further afield for services may have strengthened the willingness to travel as compared to those services that participants did not choose but rather 'had' to utilise as part of their treatment.

### Possible Conflicts or Bias

Two possible impacts or influences on responses were noted among the patient group. These included those with a direct family member who had previously had cancer and those who were currently or formerly a health care professional.

The interviewees included two stakeholders and four patients who had been directly involved in the care of an immediate family member who had a cancer diagnosis. As Paling (2003) discussed, a patient's assessment of risk associated with their cancer diagnosis is determined not by the facts but by emotions. Therefore, doctors may well have been able to provide a factual discussion of the patient's diagnosis and treatment options but this may have been skewed by the patient's feelings, which will in turn alter the way that their experience was perceived and remembered. Instances and incidences involving the cancer experience of their loved one may have impacted on how they remembered their own experiences or how they perceived the importance of certain elements.

Likewise, two stakeholders were noted to be former health care professionals and now serving as elected representatives at various levels of government. Additionally, two patients were former health care professionals. This had the capacity to skew the perceptions of their experiences by virtue of their professional exposure and knowledge. One study found that nurses as cancer patients were impacted by the fact that they had seen 'the worst of it all' in their professional setting and thus experienced more of a shock when they became a patient themselves (DeMarco, Picard & Agretelis 2004). Their health background was perceived as an advantage, because of their higher understanding of the system and the subsequent ability to access resources. This was supported by another study that found a small decline in mental health issues for nurses as cancer patients because of their capacity to navigate the health system (Kroenke et al. 2004). However, it was likewise seen as a liability as nurses were perceived as able to operate with less information and less emotional support from health staff as they should be able to 'take it' (DeMarco, Picard & Agretelis 2004). This was demonstrated by the fact that health professionals were less likely to join a support group because of the perception (including self-perception) that this would be unnecessary for a person with their level of knowledge and networks. However, the need for supportive people or resources still existed for health staff, and Kroenke et al. (2004) found that these health professionals were prone to feelings of a lack of control and difficulties accessing the assistance they required. Therefore, the capacity for a health care professional to discuss their experience devoid of any impact from their professional background, and for the extent of this impact to be known, is limited and this can alter the way in which those experiences are perceived.

## Data Collection

Another limitation of the findings was data collection, be it documents or recruitment of certain participants to cover a more comprehensive viewpoint. First, there was a lack of inclusion of particular key groups within the radiation therapy services debate. This was particularly notable in the case of the media. One journalist was prolific in discussing the need for a radiation therapy service in the North West and represented the significant majority of public discussion on the issue in the lead up to the 2010 federal election. Requests were made on multiple occasions for an interview with the journalist but no opportunity was made possible. No other member of the media was identified as contributing substantially to the debate. This meant the full extent of the media's beliefs and position in this instance were drawn solely from document analysis, without the capacity to substantiate the conclusions drawn from this via an interview.

Similarly, the formal viewpoints of the various health professions were unable to be represented via an interview and through very limited document analysis. A request to interview a representative of the nursing profession's representative body, the Australian Nursing and Midwifery Federation (Tasmania), or for the contact details of a suitable nursing professional in the area of radiation therapy in the North West were not met with success. Requests to interview a representative of the AMA (Tasmania) were also unsuccessful, as were requests to interview a key health professional involved in the delivery of radiation therapy services at the newly established North West Regional Cancer Centre. The reasons for this lack of involvement cannot be known. However, a recent study did find that 73.8% of radiation therapists interviewed saw time and workload as the main barrier to their participation in research, with the next most prevalent barrier – support – only 14.1% (Halkett et al. 2017). This indicates the significance of time restrictions for this particular health profession. This limited the view of the health profession largely to that of medical professionals, whose viewpoints were known through multiple media statements by the AMA and through stakeholder interviews.

Finally, viewpoints were limited through a lack of access to certain documents that might have further aided analysis. A Right To Information claim resulted in references to several

documents, particularly in relation to the viability of a radiation therapy service and the recruitment and retention plan. Some of these were noted by the then Health Minister as requirements for the project to proceed. However, access to these particular documents could not be granted because of restrictions on their classification. Therefore their contents, and the impact on the overall conclusions drawn, cannot be known.

## Sample Size

In addition to representation of certain viewpoints, the sample size also needs to be considered. There is overall a lack of consistency around the appropriate number of interviews to complete in order to obtain data saturation. Guest et al (2006) provided a summary of multiple studies that looked at the 'right' sample size:

Bernard (2000:178) observed that most ethnographic studies are based on **thirty-sixty** interviews, while Bertaux (1981) argued that **fifteen** is the smallest acceptable sample size in qualitative research. Morse (1994:225) outlined more detailed guidelines. She recommended at least **six** participants for phenomenological studies; approximately **thirty-fifty** participants for ethnographies, grounded theory studies, and ethnoscience studies; and **one hundred to two hundred** units of the item being studied in qualitative ethology. Creswell's (1998) ranges are a little different. He recommended between **five and twenty-five** interviews for a phenomenological study and **twenty-thirty** for a grounded theory study. Kuzel (1992:41) tied his recommendations to sample heterogeneity and research objectives, recommending **six to eight** interviews for a homogeneous sample and **twelve to twenty** data sources 'when looking for disconfirming evidence or trying to achieve maximum variation.' None of these works present evidence for their recommendations. (61-62)

With a total of 38 participants interviewed, the study does achieve a sample size that is consistent with a majority of these viewpoints. However, it cannot be known what further data would have been revealed as a consequence of a larger sample size and how this data may have impacted on the overall findings. It is also a consideration that those responding

to recruitment strategies may be more likely to have a personality that predisposes them to participation and providing their viewpoint. This could result in a particular type of participant being more heavily featured in the subsequent sample, one who is more readily able to discuss personal opinion or more passionate about their experience and their reflections. Therefore, those with more strongly held beliefs and experiences might have been more inclined to participate. Once again, this cannot be known and was unlikely to be avoided given the opt-in nature of the patient recruitment strategy.

## Interviewer Bias

A separate consideration is the impact of the interviewer on the findings. This research involved the undertaking of semi-structured interviews by a single researcher, the Doctoral candidate. Conducting interviews using one researcher does introduce an element of bias as no interviewer is able to remove bias and assumptions altogether (Tong, Sainsbury & Craig 2007). This bias can come through during the interview process and may alter the way questions are asked and the responses of participants. Although the semi-structured questions were pre-prepared in conjunction with the Doctoral supervisors, and approved by the Human Research Ethics Committee, the nature of the interviews meant that additional questions were added during the course of the interview. This was to clarify points or seek elaboration on pertinent matters. The introduction of such additional questions may have altered the emphasis or focus that the participant perceived the interview to be taking, and thereby altered their responses. Additionally, body language, tone of voice and inflection on certain words by the interviewer may also have altered the way the participant perceived the interviewer, felt during the interview and responded to questions (Tong, Sainsbury & Craig 2007). While such impacts cannot be mitigated entirely, they can be considered as a possible source of limitation on the findings of this research.

## Limitations of the Theory

The ACF was found to be applicable to case study of radiation therapy services in North West Tasmania but is not without its limitations. As discussed in the Literature Review, the ACF has been questioned in regard to its applicability to complex health issues (Breton et al.

2008) as well as the long term stability of coalitions (Cairney 2007). Stability of coalitions was a limitation also raised in a systematic review of applications of the ACF (Weible, Sabatier & McQueen 2009), with questions raised about the capacity of the ACF to explain the composition and defection of members. Such questions do not seem applicable to the issue of radiation therapy services, however, as the one identifiable coalition did not appear to have notable defections or a substantial change in membership during the period of the policy debate. The state government, which had favoured expansion of the Launceston service over establishment of a new service in the North West, only proceeded to establish such a service after the federal government made specific funding available for this. This could not be reasonably described as a defection by State Health Policy Actors, especially when some of these same actors continued to demonstrate concern about the sustainability of the service six years after the funding commitment during stakeholder interviews. The medical profession, represented by the AMA, did not change its view towards the establishment of a service even after the Centre's construction. However, the same limitation of the ACF – composition and defection of members – might well have applied to a competing coalition. It may be feasible that those who lobbied for such a service had support from other actors who disengaged from the policy debate before a formal coalition could be established, such as members of the public signing the petition but never pursuing the issue further or moving on to another cause of more interest. The data collected was unable to support a second coalition but there may have been the foundations of one if member stability had been achieved early on.

## Summary

The discussion presented in this chapter has provided a comprehensive examination of the findings of both the document analysis and the interviews with stakeholders, patients and family. It has also presented a robust and valid explanation of how policy change was achieved in the instance of radiation therapy services in North West Tasmania. The core research aim – to examine the motivation behind the public policy change in regard to radiation therapy services in North West Tasmania, with particular examination of the case of the establishment of radiation therapy services in North West Tasmania – has been systematically analysed, discussed and answered with reference to all data collected and its

external validity, strengths and limitations has been established. A full summary and overview of all aspects of this research project, from outlining the research problem, to methods, literature review, data collection and analysis, is provided in the final chapter – Conclusion.



## Chapter 7: Conclusion

This thesis has examined the motivations behind policy changes to radiation therapy services for those in the North West region of Tasmania. In examining this issue it has become apparent that accessibility – the face-value motivation for this policy change – is a relative term that can be achieved and viewed in multiple ways and that the key question to be answered is how public policy has been used to alter radiation therapy service delivery and what the motivations behind these policy changes have been. At the core of this analysis and discussion has been the establishment of radiation therapy services via the building of the North West Regional Cancer Centre. The opening of this Centre created a new treatment option in the region, one that had not been available locally in the past. This new option thereby created enhanced geographic accessibility by virtue of proximity. However, discussion has focused on why this Centre was opened, who lobbied for it and how the public policy process was used to achieve it.

### Literature Review

The Literature Review examined several core aspects of this research focus. It discussed in detail the history of cancer services, including radiation therapy, in Tasmania. These services included chemotherapy being accessible across all regions and radiation therapy being centered in the North and South. There was also a notable inclusion of visiting specialists via outpatient clinics that allowed a number of services to be delivered into the North West. This ranged from consultation and follow-up appointments to a fly-in, fly-out medical oncologist providing all medical oncology services to the North West from Melbourne for a period in excess of three years. The need for such visiting services or non-resident specialists focused discussion on the issues of recruitment and retention for specialist services in the North West (Rural and Regional Health Australia 2012; DLA Phillips Fox 2010).

A history of plans that changed or attempted to change the way health services were delivered in Tasmania was also discussed as part of a review of radiation therapy services in Tasmania. These plans largely expressed the need to centralize a number of services within

Tasmania in order to create sustainability and often services in the North West and West were targeted as part of this (Department of Health and Human Services 2007, 2015b; Expert Advisory Group 2004). These plans provided a clear indication of the policy beliefs of the successive state governments that proposed them, as well as the health professional bodies that supported and contributed to their development, which were sustainability, safety and the reality of financial constraints on health budgets.

Examination of these proposals highlighted another important aspect of this research, which was the unique nature of politics in Tasmania and particularly in the North West. People in the North West have demonstrated a high degree of support for their local services and a high degree of concern at any loss to those services (McCall 2010; Shannon 2005, 2010). The North West remains prone to regionalism and this can drive the political agenda. Tasmania has a less common preferential voting system (the Hare Clark method) and this has resulted in a higher level of responsiveness to local issues by candidates, sometimes in opposition to the views of their own party or colleagues. The highly marginal nature of the federal electorate of Braddon has amplified this sense of local issue politicking, which was exemplified by the Howard-led takeover of the Mersey Community Hospital in the region (Grube 2010). Such maneuvers appear to have primed the North West community's expectations that local issues would resonate more deeply with candidates and that elections can be won and lost on single issues in key marginal seats. This can in part answer why the federal political parties were keen to compete for a funding commitment for radiation therapy services, as this was seen as the local issue during that particular federal election.

The desire to retain local services and indeed to expand them to create further treatment options in the North West may have extended from a perception of the health inequalities that are prevalent in rural and remote regions (Coory, Ho & Jordan 2013), and the Literature Review examined this further. Rural and regional cancer patients were found to have: lower levels of referral for radiation therapy (DLA Phillips Fox 2010); fewer treatment options presented, discussed or taken up (Senate Community Affairs References Committee 2005); anecdotal instances of foregoing treatment that was not available locally (DLA Phillips Fox 2010); higher mortality rates (Rural Doctors Association of Australia 2005); and higher levels of modifiable lifestyle risk factors that can increase the chance of certain cancer types

(Senate Community Affairs References Committee 2005). The review of the literature pertaining to rural and remote health inequalities found that the issue is firmly on the political agenda nationally, given Australia's geographic size (Fox & Boyce 2014). However, there was insufficient evidence that North West Tasmania was particularly disadvantaged in terms of travelling to access services (Deloitte Access Economics 2011). This evidence seemed at odds with the perceived community sentiments and the policy outcome that had resulted in radiation therapy services being established, and thus presented the focus of the data collection: what and/or who prompted this policy change?

The theory of policy analysis was the second section of the Literature Review, which examined the most likely fit between this research focus and the models of policy analysis most commonly used in health research. Traditional theories, such as pluralism and elitism, were examined but further discussion was given to those theories that had developed and extended these. The ACF (Sabatier 1986), the Policy Narratives Framework (PNF) (Shanahan, Jones & McBeth 2011) and Coalition Structuring (CS) (Breton et al. 2008) were developed based on similar premises, with each extending the foundations of the others. However, CS was later found to be less applicable in this particular case study. Particular attention instead was given to the increased use of the ACF in health policy analysis, away from its original focus of environment and energy policy.

The ACF, its origins, hypotheses and applications in research were all discussed in great detail. Its origins as a way to merge top-down and bottom-up approaches of policy analysis (Sabatier 1986) were further developed through a series of articles, books and papers by key authors involved in its development. Three shortcomings of existing policy analysis models gave rise to the development of the ACF, being inadequate discussion of causality, limitations in implementation theory, and the insufficient role of scientific and technical information into the policy process (Weible, Sabatier & McQueen 2009). The ACF was distinguished from other similar theories based on its focus on beliefs rather than by the exercise of power (Sabatier & Weible 2007), although power is still evident in the beliefs and resources of actors and can impact on the capacity for policy change to be implemented.

The factors that made a coalition, according to the ACF, were outlined as the alignment of policy beliefs by identifiable actors who engage in coordinated and non-trivial action over a

prolonged period of time (Sabatier & Weible 2007). These beliefs could be ascribed one of three levels of value – deep core, policy or secondary – with policy beliefs being the level of belief that determined a coalition (Sabatier & Jenkins-Smith 1999). Multiple possible coalitions could be perceived prior to data collection, such as health professionals, elected representatives at different levels of government, advocacy groups and patients themselves.

The policy subsystem was discussed and determined to be regional in nature (specifically NW Tasmania) and disease specific (cancer services). This was determined by the differences in regional as opposed to metropolitan health services delivery, the localism inherent within Tasmania (Crowley 2000) and the service-specific nature of the actors involved and the participants who were interviewed as part of the data collection (Sabatier & Weible 2007). This subsystem was defined by its own set of relatively stable parameters and basic attributes that defined it.

The outcome of policy debate within this defined system was discussed as policy change. This was triggered through multiple means: shocks to the external environment; policy learning; internal shocks; and alternate dispute resolution (Weible, Sabatier & McQueen 2009). However, it was further noted that policy learning does not always result in policy change, with multiple other factors impacting on the capacity for learning to override power, personal ideologies and the involvement of policy entrepreneurs (Dolowitz & Marhs 2000; Moyson 2014). Indeed, this was supported by this research, where no evidence of policy learning was evident but instead intervention but a higher level of government altered the policy debate and enacted policy change.

Underpinning the ACF were multiple hypotheses, grouped into three categories of Policy Change, Policy Learning and Coalitions (Jenkins-Smith et al. 2014). Two of these hypotheses were tested as part of this study, one being confirmed and the other being unsupported.

The ACF has been applied to extend the way in which health policy debates are examined and explained. In particular, research was reviewed that looked at the power and resources of coalitions in the tobacco industry. These research articles reaffirmed that power tends to remain with whichever coalition has the majority of the financial resources until the depth and weight of scientific evidence forces a policy change through community pressure

(Cairney 2007; Farquharson 2003). This research both supported and contrasted with the findings of this thesis. These and other studies concluded that power rested with the coalition that controlled the policy agenda (Kershaw, Swanson & Stucchi 2017). However, this thesis has found that power in the case of radiation therapy did not rest with the traditionally powerful and privileged position of the medical profession, but instead with policy entrepreneurs who used the community's status as voters to guide political commitments by framing the issue as one of local importance. It supported the thesis, however, in that both showed that scientific evidence was routinely ignored, reframed or disputed to suit the narrative of the other side of the policy debate. The weight of evidence in relation to the harms of tobacco took a number of decades to overpower the resources of the tobacco coalitions. However, the force of evidence on sustainability and recruitment presented by the health and policy coalition has not, to this date, overpowered the desire to provide a radiation therapy service.

Analysis of the ACF in health policy also looked at how coalitions can pitch their lobbying efforts above the level of government directly related to the policy subsystem if this can be advantageous to that coalition (Princen 2007; Shannon 2010). This view was supported by the findings of this thesis, that the federal government had been successfully lobbied by media representations of perceived community desire and had overridden the responsibility of the state when it came to health service provision.

The Literature Review also specifically focused on several articles that related to the health system in Tasmania. These articles found evidence consistent with this thesis that a coalition comprising of health professionals and health bureaucrats has operated consistently in the state for a period of more than a decade (Shannon 2005, 2009). The articles also reaffirm the finding that regional attitudes had resulted in a concern over the loss of any services and that candidates were responsive to these issues. One of these articles in particular confirmed the findings of this thesis that the community may not organise itself as a formal coalition in the policy debate but that their interests are represented by those politicians vying for community support instead (Shannon 2009).

Research in health policy using the ACF also resulted in findings about emotion and policy learning. Several articles reaffirmed the findings of this thesis that some health issues are

considered to be emotive and that scientific evidence is often unable to counteract the significance placed on this emotion (Gathje 2009; Schorn 2005). Policy learning may not occur between coalitions where policy makers fear the emotion attached to the issue and the consequences of policy decisions that do not respond appropriately to this emotion.

The examination of this breadth of research utilising the ACF for health policy analysis confirmed that the ACF was a sound theoretical framework that could be used to test the research aims of this thesis. The capacity for the ACF to explain policy change in complex, emotive areas of health, with competing beliefs and actors involved, seemed well suited to the debate over radiation therapy services. Based on this selection, a methodology for determining the reasons for the change in policy on radiation therapy was developed.

## Methodology

The methodology chapter outlined the process undertaken to collect data through document analysis and semi-structured interviews. The mix of two data sources was considered necessary to gauge the publicly stated viewpoints of stakeholders but also the thoughts and rationales of the community through the interviewing of patients and their family, who were not easily found among the document analysis. Interviews allowed the view of the community, as well as the personal views of stakeholders, to fill in the gaps created through the document analysis. This dual approach to data collection was a strength of the methodology, as a significant component of the analysis and findings would have been lost without both parts. Document analysis alone would have provided only minimal evidence of a single coalition without capacity to verify this finding. Equally, the truly political nature of the policy debate and subsequent policy decisions would not have been found without face-to-face discussions with those who had been involved in the policy debate.

Another strength of the methodology was the recruitment process. Being able to directly identify key actors from document analysis and approach them about participation in an interview increased the likelihood of gathering the most relevant data possible. An opt-in system, rather than direct approach, would have reduced the chances of adequate coverage of stakeholder opinions and thereby weakened the results. This can be exemplified by the

number of direct approaches that were declined because of time constraints, indicating that participation in a research project may not have been considered by many stakeholders had they not been approached directly.

Recruitment for patients and families was another strength, but for the opposite reasons for stakeholders. By using an opt-in system the capacity for patients and family to determine their involvement could be increased, rather than placing any sense of expectation on them to participate. This ensured that only those truly interested in participation would approach to be interviewed and limited any possibility for pressure or trauma to be visited upon those who had had a life-changing health experience. As discussed above, cancer is an emotive issue and finding those who feel willing and able to discuss the toll of this on their lives was an important ethical consideration.

The methodology also had its limitations. The opt-in system of recruitment was equally as limiting as it was empowering as it ensured that only those who wanted to express an opinion were recruited. There are many patients who may have been unaware of the recruitment advertising, or who did not feel willing to participate in an interview, whose views would have provided further insight into this research. These viewpoints cannot be known and their significance overall cannot be gauged. This is equally as true for those who were approached to participate and declined involvement. These stakeholders represented a number of key actor groups, including the medical and nursing professions as well as the media. The absence of the expressed view of these groups is also an unknown impact on the robustness of the results.

A final weakness of the methodology was also the reality of document searches. Certain keywords and databases were manually selected and these produced the results that were incorporated in the document analysis. While every effort was made to ensure keywords provided a comprehensive reflection of the research aim it is possible that other keywords may have yielded further results that could have added to, and possibly changed, the findings. With such a vast amount of information available it is not possible, nor would it ever be possible, to capture all the relevant documents. This is further weakened by the process of manually reviewing abstracts and summaries in order to select those documents that would be fully examined. An individual needs to make a subjective decision about the

content of a document and its relevance to the research aims. This can and indeed would result in some documents being overlooked or deemed irrelevant when they may well have contained information that could impact on the findings.

These limitations were mitigated by the use of rigorous inclusion and exclusion criteria, however, as well as a test of databases prior to beginning the document search. As outlined in the Methods chapter, inclusion and exclusion criteria ensured that searches only captured the most recent and relevant documents pertaining to the research aim. These criteria were tested by using a limited time span search of several databases to gauge the usefulness of those databases as well as the typical numbers of search results yielded. This allowed the most relevant databases to be used and for key words to be tested before being used.

## Results

A comprehensive range of data was gathered and the findings discussed across three chapters –Results I, Results II and Discussion. The findings between both data sources provided consistent evidence that a single coalition was identifiable within the policy subsystem, a health and policy coalition. This coalition, comprised of health bureaucrats and health professionals, could be seen as consistently collaborating across a number of health issues and reform initiatives to promote sustainable health services, patient safety and service consolidation where staffing, material resource and budget constraints dictated it. This view extended to the delivery of radiation therapy in the North West of Tasmania. The service was considered unnecessary in the region because of the close proximity of existing services, and considered unsustainable because of the inability to recruit and retain the staff required to run such a service. Geographic accessibility was not considered the paramount concern for regional patients by this group. Instead, accessibility was considered achievable by supporting transport and accommodation services, thereby improving the sustainability of the service and patient safety.

However, both the document analysis and the semi-structured interviews failed to provide evidence of a consistent, non-trivial coalition of actors opposed to the policy position of the health and policy coalition, as would be required to meet the definition of a coalition under the ACF. The view of accessibility was discussed late in the debate among the media and the



federal government and opposition (Ford 2010; Pippas 2010; Tasmania 2010a). The issue was quickly framed as one of need for the community and a political priority. Geographic accessibility became a necessity by the Centre's advocates. It was also discussed inconsistently among the patient and community advocate groups, with no uniform view of the need for geographic accessibility. All patients who had been required to travel for treatment were not concerned by this need to travel. Some patients who had not had to travel for treatment also seemed unconcerned with the idea of needing to travel and some patients had made the choice to travel further than was necessary in order to access a wider health or personal network. Those most strongly supportive of the geographic accessibility were a small number of patients and two stakeholders. This mix of views demonstrated a lack of consistency that would need to underpin a formal coalition. The lack of a second coalition was discussed at length and the notion of the policy entrepreneur in shaping the debate and drawing support to it was found to be the most likely explanation, although still unable to explain the lack of other coalition members. The federal government and/or the media are the most likely actors to fit the role of the policy entrepreneur.

## Discussion

Discussion of the findings focused extensively on what drove policy change in this instance, if it were not driven by a formal coalition. Political strategy was found to be the most likely impetus for change, which was supported by the late inclusion of the media and federal political parties into the policy debate and the timing of funding commitments with a marginal election campaign. No long-standing plan by a federal government, state government or lobby group to open a radiation therapy service in the North West of Tasmania highlighted the political opportunism of the decision and the impact of federal intervention into the state responsibility of health. This finding supported the ACF's Policy Change Hypothesis No. 2 (Jenkins-Smith et al. 2014) in regard to hierarchically imposed change and also served to reinforce the notions of boundedly rational policy making as well as localism or regionalism within the North West population. The paths to policy change were also considered (Schlager 2007), with a mix of external and internal shocks providing a likely explanation. The 2007 funding commitment for a linear accelerator went to the North rather than the North West, creating a 'shock' when announced in 2009 that coincided with

increased vocal demand for a service in the North West. This can be seen as a possible catalyst that culminated in the second external shock, the funding commitment of 2010 by the federal government, who sat outside of the policy subsystem. Internally, a local philanthropist provided a considerable donation in early 2010 to the purchase of an MRI and the training of radiation therapists, which added momentum to the discussion and added to the sense of community support.

## Conclusions

The aim of this thesis was to answer the question of why the policy decision was made to introduce a local radiation therapy service in NW Tasmania. This was answered by applying the ACF to the case study and analysing the documents and semi-structured interviews with stakeholders, patients and family.

Firstly, literature relating to the relevant aspects of this research were sourced. This included an overview of Tasmania's unique political context, the current distribution of cancer services within Tasmania, and the issue of accessibility of cancer services by people in rural and remote areas (which includes NW Tasmania). This provided context to understand why the accessibility of radiation therapy services was considered important within NW Tasmania, including the history the region had in regards to retaining and improving its existing service delivery.

To provide a basis for analysing policy decisions, literature in relation to various relevant policy analysis methodologies were presented and discussed in regards to their applicability to this particular case study. From this, the ACF was found to be the most likely framework to aid the analysis of this policy decision and further detailed information was provided on it, its origins, its hypotheses and its application. Multiple studies that applied the ACF to the analysis of health policy decisions were then drawn into the Literature Review to provide insight into how the ACF had been used in this particular policy sphere. These studies varied in the power dynamics between coalitions, the number of coalitions, the stability and continuity of these coalitions, the resources each coalition had, the role of the public in effecting change, and the role of information in creating policy learning.

From here, the research question was tested through the process of data collection. First, documents relating to cancer services in Tasmania, with particular regard to NW Tasmania, were sourced via databases and manual searches. The ACF was applied to this to provide context-specific details in regards to cancer services in NW Tasmania, as well as to gauge the expressed policy beliefs of major actors over a period of 17 years. This included beliefs expressed by various levels of government, community advocates, media, members of the general public, health professionals and political candidates.

The second source of data was interviews with stakeholders, patients and family members. These offered a firsthand perspective of policy beliefs across a single point in time and added the much-needed perspective of the cancer patient cohort that had been lacking as a consequence of the document analysis.

Both the document analysis and the interviews were analysed using the ACF to determine the likely makeup of coalitions, their expressed beliefs, the level of these expressed beliefs, their policy positions, the coordinated actions, the continuity of the coalitions and evidence of any resulting policy learning or policy change. This information was presented as key beliefs expressed by the interviewees (in Results II) as these interviews were conducted at a single point in time, and in chronological order by key actor groups in the document analysis as these documents expressed a view by groups over a prolonged period of time. This showed which beliefs were expressed consistently by which groups of what period, making it easier to determine which coalitions demonstrated consistency over the period of time required under the ACF (10 years or more). This ultimately found only one formally identifiable coalition, as per the ACF, defined by its consistent beliefs and coordinated action over the established amount of time required, as well as strong evidence of involvement by one or more policy entrepreneurs. Various explanations in regards to the lack of a second coalition were also examined, including latent actors, quiescent subsystems or politicians as a second coalition, but none were able to withstand application of the ACF to test their definition as a coalition. While further explanations of single coalition subsystems continue to emerge through further studies, the explanation most supported by the evidence in this study is that only one coalition existed in competition with one or more policy entrepreneurs.

The answer to the research question was ultimately that political strategy was the most likely impetus for this change, in as much as such a question can ever be definitively answered. This had come from a possible pool of three explanations of policy change: political strategy; demonstrated need; or community lobbying for change. The research found that geographic accessibility was not a universally-held priority for the local community and in fact the local community were inconsistent in expressing a desire to have a local radiation therapy service. Geographic accessibility of radiation therapy services in the North West was instead achieved by public policy brought down as part of a political strategy. The local media created a sense of community support for such a service and this created an opportunity for the federal parties to meet this perceived desire and win political support. This conclusion provides support to the notion that the division of federal and state responsibilities on health have become blurred and that power can be exercised to achieve change that is considered politically advantageous.

This analysis demonstrated the applicability of the ACF to this particular case study. The ACF was an applicable framework with which to examine the case study of the North West Regional Cancer Centre as its establishment was explained through careful analysis of the four triggers for policy change. Of these four triggers there could be found both internal and external shocks to the policy subsystem. A local philanthropist's substantial donation to an MRI and radiation therapist scholarships created an internal shock by providing renewed media attention and a sense that the service could be funded. This fed into the increased sense of community attention, driven by the media, which in turn led to dual commitments during the 2010 federal election. These commitments were the external shock that forced acquiescence by the state government, who had, until that time, been unwilling to move immediately on establishing a North West radiation therapy service.

The ACF was also able to provide a framework by which to identify one formal coalition and the beliefs of this coalition and the other major actors involved in the policy subsystem, even if those groups were not part of a formal coalition. Identifying the policy beliefs allowed the relevance and importance of the issue to certain groups and people and to understand the values that underpin local delivery of radiation therapy services. The study was perhaps limited, however, in the capacity to trace coalition stability and membership over time, as has been noted in previous applications of the ACF (Weible, Sabatier & McQueen 2009).

Although the views of the AMA and state government remained stable over the period of the policy debate, and therefore the coalition remained stable, the competing coalition may have had retention and defection over members over time, thus reducing the capacity for a formal coalition to be established. The full extent of this cannot be known in the scope of this research.

The use of the ACF in this case study also created an opportunity for the framework to be further developed. A policy change that occurs in a single coalition subsystem, especially when the change is contrary to the policy beliefs of that coalition, is something to be potentially added to the framework. The role of the policy entrepreneur, without support from any identifiable actors, could be included as an alternative to a formal coalition. This explanation would fit well with the case study of radiation therapy services in North West Tasmania.

The inclusion of a policy entrepreneur to this case study, be it the media or even political parties or governments, can be further explained by the inclusion of bounded rationality and localism into the decision-making strategies of policymakers. A second coalition was found to be absent and concerted effort by policy entrepreneurs was found. The impact of this was on the decision to change (or force the change) of the current policy was significant. But it bounded rationality and localism that made the policymakers more susceptible to the shaped and targeted narrative of the policy entrepreneurs. The aspirational level of the policymakers in this instance was to be elected or re-elected during the 2010 federal election. While sufficient evidence was presented that questioned the sustainability of a regional radiation therapy service, the policymakers used pre-determined methods of assessing information (gauging public opinion and expectations) and went with the packaged response best able to meet this aspiration. No further data was gathered beyond this and no continued opposition was able to detract from it. This serves as evidence that policymakers used bounded rationality to act on their decisions. However, it was the sense of localism among the North West population that fueled this sense of bounded rationality. Strong local sentiments were expressed through the patient and family interviews, and an equally strong sense of community expectation was expressed through the local media. The right to access radiation therapy in the local area was seen as an imperative, not for the sake of patient safety but for the sake of North West equity with other regions and to foster a sense

of the North West as being heard and seen by politicians and governments alike. To use a suitable analogy, localism was the dry kindling and bounded rationality was the match.

The way in which bounded rationality can so potently outweigh the policy lobbying efforts of a single coalition provides significant scope for consideration within the ACF. While the policy broker is discussed as being almost neutral and detached from the process to being active participants in literature, bounded rationality shows how active a policy broker can actually be.

What this research provides is the opportunity to understand the power and potential of the media and of federal intervention in state responsibilities through the harnessing of emotive issues that can garner general public support. Understanding the ways in which policy can change, even in the face of a credible opposition and evidence to the contrary, allows the complexities of the policy process to be further explored and acknowledged.

What this research does not provide is a clear explanation of policy change that can fit with the ACF as it is currently structured. It is theoretically unanswered as it stands but provides scope for theoretical development. What it also lacks is a comprehensive discussion of the full range of viewpoints relating to this issue. Key voices were unheard or unknown, and could only reduce the fullness of the findings, but was also beyond the capacity and control of the author.

If this research were to be replicated, there are some reflections that would improve rigour. The absence of any representative from the media, given their key role as policy entrepreneurs, was a significant gap in source of interview data. A recruitment design that pursued an interview with key media representatives, even if not the main journalist involved but perhaps their editor, might have resulted in a more successful response. Beginning the research earlier would be another modification. This research commenced several years after the funding commitment was made and construction on the North West Regional Cancer Centre had started. Beginning the research at the point in time when the issue began to be discussed more widely, especially in the media, would have allowed better following of the debate and timely access to media and public discourse in real time. As it was, interviews spanned the period when the Centre first began delivering radiation

therapy, meaning some patients had been treated in the North West and others patients had been treated in other regions. If instead all patient interviews were with those who had to access radiation therapy from outside the region the experiences would have been more consistent across this group and focused more on whether a local service was something they wanted or would have wanted.

This research creates an opportunity for further research to be undertaken to gauge the extent of political strategy as an impetus of policy change and the impact of localism or regionalism on policy making.

## Personal Reflections

The process of researching public policy and radiation therapy services in North West Tasmania has turned out to be a very different one to what I had first anticipated. As someone with no prior history working in oncology and no firsthand experience of witnessing a patient's journey through a cancer diagnosis, I was uninformed in regard to the policy subsystem. I was also unfamiliar with major theories of policy analysis. I had never heard of the ACF prior to my search for a suitable theory to use in this thesis.

My expectations had been based on poorly understood notions of regionalism, based on the rationale that those in regional areas always fared worse in terms of access to services. My assumption was that providing as many services close to home was always in the best interests of the patient, that there was widespread concern among North West residents about travel to treatment and the need to travel was based on medical specialists referring patients to the centre from they worked predominantly. This had been based on a story I had heard from one widower whose wife had been required to drive from the North West to Launceston each day, with her non-school aged son, for chemotherapy because that was what her medical oncologist had told her to do and that was where the oncologist was based. She had been unaware that chemotherapy was available approximately 15 minutes away from her home. My desire to conduct research in this area was born out of that single story.

However, the results of this research have shown one thing in relation to that particular story – that public policy had very little to do with the outcome for that patient. Public policy has instead been used to harness political opportunity, which, in the case of radiation therapy services, resulted in the establishment of the North West Regional Cancer Centre. Will the establishment of the Centre mean medical specialists no longer refer patients to Launceston simply because this is where the specialist is based? This is not yet known and would be worthy of examination, as the Centre was opened to prevent unnecessary patient travel. It would be equally as interesting to examine whether referral rates to the new Centre have been comparable to expectations or whether some patients are choosing Launceston, Hobart or further afield for treatment. If referrals do not eventuate as expected, or if some patients are still choosing to travel, this would create questions again around the concept of accessibility.

In conclusion, the North West region of Tasmania now has a state-of-the-art cancer centre that has provided not only a greater range of services closer to home but also a sense that the North West warrants equity and investment. It will become a source of pride for the community and will change the dynamics of cancer service delivery in Tasmania for many years to come. Whether the genesis of the Centre results in the further mixing of health policy with political opportunism remains likely while the local electorate of Braddon remains a marginal seat.



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# Appendices

## Appendix 1 Inclusion and exclusion criteria for literature review

Inclusion Criteria	Exclusion Criteria	Rationale
Literature for 1986 onward/ 2000 onward	Literature prior to 1986 for the ACF, and literature prior to 2000 for identifying cancer services in North West Tasmania	1986 - The first time Sabatier published material referring to ACF  2000 – a decade prior to a major turning point in the cancer services debate in North West Tasmania
English only	Articles in languages other than English	For ease of dissemination of information and correct interpretation
Literature derived from academic databases, peer-reviewed journals; full text conference papers; local media; published books or texts; government publications and reports; material produced by political parties; material produced by cancer-related services and health profession bodies; policies and associated briefs; reports produced for government; discussion papers by field experts	Abstract only literature, partly reproduced conference papers, unpublished materials or data	For quality and reliability of literature – local media included as this is the most likely forum for statements made by candidates and elected representatives about policy initiatives
All cancer types except non-melanoma skin cancers	Non-melanoma skin cancers and non-recurrent, non-metastasized melanoma skin cancers	To limit research to those cancers treated by traditional oncological services, rather than GP-based surgical procedures; and to control size
Treatment services for diagnosed cancers	Screening, vaccination, prevention, education	To limit the scope of the research to access to treatment services, which are more location-centric
Cancer services relating to medical therapies	Cancer services relating to alternative therapies	To limit research to traditional oncological services and treatments, complimented by ancillary support services
	Literature pertaining to prevention strategies only	To limit research to patients actually experiencing cancer
Cancer services provided within Tasmania	Cancer services	To focus research on

or for Tasmanians in another state by the public health system	provided in another state for populations other than Tasmania	accessibility within Tasmania only and to public services only
Abstracts indicating a direct relevance to cancer services and to Tasmania or to the overall health system of Tasmania	Abstracts indicating that the article is not directly relevant to cancer services in Tasmania or to the overall health system	To only include those articles with are most directly relevant to the research area
Abstracts indicating analysis and discussion of the ACF as it applies to health or to the development of the Framework overall	Abstracts indicating that the ACF is not discussed or analysed in depth	To include those articles which discuss the ACF in the most detail

## Appendix 2 Coding of level of beliefs

	Deep (normative) core	Near (policy) core	Secondary aspects
Defining characteristics	Fundamental normative and ontological axioms	Fundamental policy positions concerning the basic strategies for achieving normative axioms of deep core.	Instrumental decisions and information searches necessary to implement policy core.
Scope	Part of basic personal philosophy. Applies to all policy areas.	Applies to policy area of interest (and perhaps a few more).	Specific to policy/subsystem of interest.
Susceptibility to change	Very difficult; akin to a religious conversion.	Difficult, but can occur if experience reveals serious anomalies.	Moderately easy; this is the topic of most administrative and even legislative policy-making
Illustrative components	<ol style="list-style-type: none"> <li>1) The nature of man <ol style="list-style-type: none"> <li>i) Inherently evil vs. socially redeemable.</li> <li>ii) Part of nature vs. dominion over nature.</li> <li>iii) Narrow egoists vs. contractarians.</li> </ol> </li> <li>2) Relative priority of various ultimate values: freedom, security, power, knowledge, health, love, beauty, etc.</li> <li>3) Basic criteria of distributive justice: Whose welfare counts? Relative weights of self, primary groups, all people, future generations, non-human beings, etc.</li> </ol>	<ol style="list-style-type: none"> <li>1) Proper scope of governmental vs. market activity.</li> <li>2) Proper distribution of authority among various units (e.g. levels) of government.</li> <li>3) Identification of social groups whose welfare is most critical.</li> <li>4) Orientation on substantive policy conflicts, e.g. environmental protection vs. economic development.</li> <li>5) Magnitude of perceived threat to those values.</li> <li>6) Basic choices concerning policy instruments, e.g. coercion vs. inducements vs. persuasion.</li> <li>7) Desirability of participation by various segments of society: <ol style="list-style-type: none"> <li>i) Public vs. elite participation.</li> <li>ii) Experts vs. elected officials.</li> </ol> </li> <li>8) Ability of society to solve problems in this policy area: <ol style="list-style-type: none"> <li>i) Zero-sum competition vs. potential for mutual accommodation.</li> <li>ii) Technological optimism vs. pessimism.</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>1) Most decisions concerning administrative rules, budgetary allocations, disposition of cases, statutory interpretation, and even statutory revision.</li> <li>2) Information concerning program performance, the seriousness of the problems, etc.</li> </ol>

<sup>a</sup>The policy core and secondary aspects also apply to governmental programs.

### Appendix 3 Ethics approval letter – HREC

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University of Tasmania  
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Email Human.Ethics@utas.edu.au  
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HUMAN  
RESEARCH  
ETHICS  
COMMITTEE  
(TASMANIA)  
NETWORK



25 February 2016

AssocProf Tony Barnett  
Centre for Rural Health

*Sent via email*

Dear AssocProf Barnett

**REF NO:** H0015396  
**TITLE:** Cancer services in NW Tasmania: the policy impacts. How does public policy affect accessibility of cancer services in North West Tasmania and how does this affect the experiences of patients and family

<b>Document</b>	<b>Version</b>	<b>Date</b>
Consent-form patients		18.01.2016
Consent-form stakeholders		18.01.2016
Information Sheet for Patients and Family		18.01.2016
Information Sheet for Stakeholders		18.01.2016
Interview Questions for Stakeholders		17.11.2015
Letter of invitation to identified stakeholders		18.01.2016
Letter of invitation to patients		18.01.2016
Letter of invitation to stakeholders		18.01.2016
NEAF as submitted to Tasmanian HREC		18.01.2016
Questions to patients		17.11.2015
Recruitment Poster		17.11.2015
TSRAC-Study-Protocol-Pro-Forma_813		18.01.2016

The Tasmanian Health and Medical Human Research Ethics Committee considered and approved the above documentation on **09 February 2016** to be conducted at the following site(s):

Please ensure that all investigators involved with this project have cited the approved versions of the documents listed within this letter and use only these versions in conducting this research project.

This approval constitutes ethical clearance by the Health and Medical HREC. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approvals of other bodies or authorities are required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the *National Statement on the Ethical Conduct in Human Research* (NHMRC 2007 updated 2014).

Therefore, the Chief Investigator's responsibility is to ensure that:

- (1) The individual researcher's protocol complies with the HREC approved protocol.
- (2) Modifications to the protocol do not proceed until **approval** is obtained in writing from the HREC. Please note that all requests for changes to approved documents must include a version number and date when submitted for review by the HREC.

- (3) Section 5.5.3 of the National Statement states:

Researchers have a significant responsibility in monitoring approved research as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution/s and ethical review body/ies and take prompt steps to deal with any unexpected risks.

The appropriate forms for reporting such events in relation to clinical and non-clinical trials and innovations can be located at the website below. All adverse events must be reported regardless of whether or not the event, in your opinion, is a direct effect of the therapeutic goods being tested. <http://www.utas.edu.au/research-admin/research-integrity-and-ethics-unit-rieu/human-ethics/human-research-ethics-review-process/health-and-medical-hrec/managing-your-approved-project>

- (4) All research participants must be provided with the current Patient Information Sheet and Consent Form, unless otherwise approved by the Committee.
- (5) The Committee is notified if any investigators are added to, or cease involvement with, the project.
- (6) This study has approval for four years contingent upon annual review. A *Progress Report* is to be provided on the anniversary date of your approval. Your first report is due **9 February 2017**. You will be sent a courtesy reminder closer to this due date.
- (7) A *Final Report* and a copy of the published material, either in full or abstract, must be provided at the end of the project.

Should you have any queries please do not hesitate to contact me on (03) 6226 1832.

Yours sincerely

Sarah Clarkson  
Administration Officer  
Research Integrity and Ethics Unit (RIEU)  
Division of the Deputy Vice Chancellor (Research)  
University of Tasmania  
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[www.utas.edu.au/research](http://www.utas.edu.au/research)

## Appendix 4 Ethics approval letter – amendment

Friday, 15 December 2017 at 12:50:06 PM Australian Eastern Daylight Time

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**Subject:** Notification of Amendment Approval: H0015396 Cancer services in NW Tasmania: the policy impacts. How  
**Date:** Thursday, 14 July 2016 at 4:14:45 PM Australian Eastern Standard Time  
**From:** Lauren.Black@utas.edu.au  
**To:** Tony Barnett  
**CC:** Elaine Crisp, Elizabeth Shannon, Sancia West, Lauren Black

Dear AssocProf Barnett

Ethics Ref: H0015396

Title: Cancer services in NW Tasmania: the policy impacts. How does public policy affect accessibility of cancer services in North West Tasmania and how does this affect the experiences of patients and family

This email is to confirm that the following amendment was approved by the Chair of the Tasmania Health and Medical Human Research Ethics Committee on 14/7/2016:

Advertisement expansion across various outlets

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the National Statement on Ethical Conduct in Human Research (NHMRC 2007).

This email constitutes official approval. If your circumstances require a formal letter of amendment approval, please let us know.

Should you have any queries please do not hesitate to contact me.

Kind regards

Lauren Black

--

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## Cancer Services in North West Tasmania

### INFORMATION for patients and family

#### **1. Invitation**

This study, being undertaken by researchers from the School of Health Sciences at the University of Tasmania, aims to determine how public policy affects the accessibility of cancer services in North West Tasmania and how patients or family have experienced these services.

The Research Team consists of Sancia West, PhD Candidate, School of Health Science; Associate Professor Tony Barnett, Director of the Centre for Rural Health; Dr Elaine Crisp, Lecture, School of Health Science; Dr Elizabeth Shannon, Senior Lecturer, School of Medicine; and. The research is being conducted as part of the fulfillment of a PhD thesis by Mrs West.

#### **2. What is the purpose of this study?**

The goal of the research will be to inform policy makers about the accessibility of the system and to make **practical recommendations about its improvement**.

#### **3. Why have I been invited to participate?**

The purpose of the interviews is to discuss with patients, or with the direct carers of patients, such as parents, their experiences with accessing cancer services within or from North West Tasmania. We are therefore looking for people who are 18 years or over, who have either had a cancer diagnosis or been directly responsible for the care of someone who has had a cancer diagnosis, and resided in North West Tasmania at the time they accessed cancer services. Residents can be from any part of North West Tasmania, including King Island and the West Coast.

Involvement in an interview is purely voluntary and there are no expectations placed on people to participate.

#### **4. What will I be asked to do?**

People who do agree to participate will be asked to participate as follows:

- A Participant code would be issued to you so that you are not identified directly. Please note that in a published report, such as a thesis, where direct quotations are used, some readers might be able to speculate or infer as to the identity of the participant. This is due, in some part, to the same population size of Tasmania. The risk associated with this is minimal however.
- A **face-to-face interview** with Sancia West will be arranged for a convenient time
  - This is anticipated to take 40-60 minutes



#### *Participant Information Sheet*

- A consent form will be discussed and signed at the start of the interview
- The interview will be audiotaped to allow it to be transcribed
- The interview can be postponed, cancelled or ceased by you at any time
- A **transcript** of the interview will be provided to you at your request and you can ask for any additions, alterations or deletions to the transcript to ensure it accurately represents your experiences

Interviews can be conducted in your home or an alternative venue of your choice at a time that is most convenient to you. Sancia West will personally visit you to conduct the interview, regardless of your location, and residents of King Island and other remote locations are warmly welcomed to participate.

The information will then be analyzed in conjunction with other interviews and any themes or recommendations identified may be included in the final written PhD thesis. Quotes from the interview may be used, however, all identities will be protected.

#### **5. Are there any possible benefits from participation in this study?**

Whilst there are no direct benefits offered in return for your participation, your experiences with the cancer system in Tasmania make you an invaluable source of information about the current system, which will assist in improving understanding.

#### **6. Are there any possible risks from participation in this study?**

Whilst every effort will be made to minimize possible risks during your participation, it is understood that the sensitive nature of some of the issues discussed may cause distress to some participants. If distress is felt at any time, the interview can be suspended, cancelled or postponed until a later time, and support can be accessed via the following services:

#### **SUPPORT SERVICES**

Cancer Council Tasmania: 1300 65 65 85

North West Combined Cancer Support Group (Joy): 6425 8605

Lifeline: 13 11 14

Lifelink Samaritans: 1300 364 566

CANTEEN: 6223 7550

#### **7. What if I change my mind during or after the study?**

If a participant changes their mind about their involvement in the research at any time they only need to alert a member of the Research Team of this. Participants are free to suspend, cancel or postpone their involvement at any time, including up to 4 weeks after the interview has been conducted.

All data relating to the interview will be securely stored on a password-protected hard drive by Sancia West for a minimum of 5 years after the interview..



**8. How will the results of the study be published?**

The final results of the interviews will be integrated into a PhD thesis, to be published in approximately late 2017. Results may also be included in oral and visual presentations made by the Research Team at relevant conferences and in associated presentations. However, confidentiality will be maintained at all times and identities will remain protected.

The PhD thesis will be printed in hardcopy as well as digitally and stored at the University of Tasmania Library.

**9. What if I have questions about this study?**

If you have any questions relating to this research or your participation, or if you would like to participate, please contact Sancia West on 0455 040 508 or email at [Sancia.West@utas.edu.au](mailto:Sancia.West@utas.edu.au)

This study has been approved by the Tasmanian Health and Medical Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 6254 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H0015396.

This Information Sheet is yours to keep and refer to.

## Appendix 6 List of documents included in document analysis

Document Type	Author	Year	No. of Pages
Conference Paper	Shannon, E	2010	21
Government Report	Contract Review Committee	n.d.	8
	Dept of Health	2005	7
	DHHS	n.d.	2
	DHHS	2007	180
	DHHS	2012b	20
	DHHS	2014a	34
	DHHS	2014b	16
	DHHS	2015a	74
	DHHS	2015b	92
	DLA Phillips Fox	2010	87
	Expert Advisory Group	2004	108
	Parliamentary Standing Committee of Public Works	2012	15
	Senate Community Affairs Reference Committee	2005	169
	The Commission on the Delivery of Health Services in Tasmania	2012	104
	The Commission on the Delivery of Health Services in Tasmania	2014	212
Hansard - Federal	Australia, House of Representatives	2010	2
Hansard – Tasmania	Tasmania, House of Representatives	2010a	64
	Tasmania, House of Representatives	2010b	36
	Tasmania, House of Representatives	2010c	82
	Tasmania, Legislative Council	2011	50
Information Sheet	DHHS	2009	1
Journal Article	Coory, M.D., Ho, T. & Jordan, S.J.	2013	5
	Hegney, D., Pearce, S., Rogers-Clark, C., Martin-McDonald, K. & Buikstra, E.	2005	9
	Payne, S., Jarrett, N., & Jeffs, D.	2000	8
Letter to the Editor	Anon.	2015	<1
	Boyenga, B	2016	<1

	Campbell, J	2013	<1
	Campbell, J	2014	<1
	Campbell, J	2015	<1
	Dudman, G	2015a	<1
	Dudman, G	2015b	<1
	Keay, J	2015	<1
	Lee, G	2016	<1
	Shacklock, P	2016	<1
	Wilson, J	2013	<1
Media Release	Abbott, T	2010	1
	AMA Tasmania	2010a	1
	AMA Tasmania	2010b	1
	AMA Tasmania	2010c	1
	Ferguson, M	2015	<1
News Article	ABC News	2010a	<1
	ABC News	2010b	<1
	Bevis, L	2014	<1
	Bingham, L	2009a	<1
	Bingham, L	2009b	<1
	Bingham, L	2010a	<1
	Bingham, L	2010b	<1
	Bingham, L	2011a	<1
	Bingham, L	2011b	<1
	Bingham, L	2011c	<1
	Bingham, L	2011d	<1
	Bingham, L	2012	<1
	Bingham, L	2013a	<1
	Bingham, L	2013b	<1
	Bingham, L	2014a	<1
	Bingham, L	2014b	<1
	Bingham, L	2015a	<1
	Bingham, L	2015b	<1
	Bingham, L	2015c	<1
	Bingham, L	2015d	<1

	Bingham, L	2016	<1
	Blewett, D	2007	<1
	Blewett, D	2009	<1
	Clark, N	2010	<1
	Dolan, C	2011	<1
	Dunlevy, S. & Crawley, J.	2014	<1
	Ford, S	2007a	<1
	Ford, S	2007b	<1
	Ford, S	2010	<1
	Livingston, A	2010	<1
	News.com.au	2010	<1
	Ogilvie, F	2012	<1
	Pippos, C	2010	<1
	Smiley, S	2015	<1
	Speers, C	2010	<1
	Stephens, J	2014	<1
	The Advocate	2007	<1
	The Advocate	2010a	<1
	The Advocate	2010b	<1
	The Advocate	2010c	<1
	The Advocate	2010d	<1
	The Advocate	2010e	<1
	The Advocate	2010f	<1
	The Advocate	2010g	<1
	The Advocate	2015a	<1
	The Advocate	2015b	<1
	The Advocate	2016	<1
	Whiteley, B	2009	<1
Non- Govt Report	Adams, P., Hardwick, J., Embree, V., Sinclair, S., Conn, B., & Bishop, J.	2009	52
	Australasian College of Physical Scientists and Engineers in Medicine, Royal Australian and New Zealand College of Radiologists, & Australian Institute of Radiography	2012	12

	Clinical Oncological Society of Australia	2006	45
	North West Radiotherapy Clinical Expert Panel	2011	55
Petition	Citizens of Tasmania	2010	1
Submission	Cancer Clinical Advisory Group	2014	16
	DHHS	2012a	72
	DHHS	2013b	10
	National Rural Health Alliance	2005	12
	Rural Doctors Assoc. of Australia	2005	7

## RESEARCH ARTICLE

# A Recipe for Success: localism and bounded rationality in lobbying for radiation therapy services in North West Tasmania

S West, E Shannon, E Crisp and T Barnett

### Abstract

**Objective:** Describes where bounded rationality and localism are evident in the debate over the introduction of radiation therapy services in North West Tasmania and how this affected the delivery of the message from each side.

**Design:** Semi-structured interviews with stakeholders and patients/family over an eight month period in 2016 are contrasted with viewpoints identified via document analysis.

**Setting:** North West Tasmania.

**Main Outcome Measures:** The mechanisms for policy change and the policy beliefs of each side are examined with the intention of understanding how bounded rationality and a sense of localism can combine to effect policy change.

**Results:** In the instance of radiation therapy services in North West Tasmania, a policy debate was originally

waged between medical professionals and policy makers opposed to a local service on one side and a handful of policy actors advocating for a local service on the other. Those in favour of a local radiation therapy service harnessed a sense of localism to project the perception of widespread community support for the proposal and secured funding commitments during the 2010 Federal Election campaign.

**Conclusions:** There is evidence of bounded rationality from both the stakeholder and patient groups, as well as a strong sentiment of localism expressed by patients and community advocates. Through understanding this particular case, health service managers can determine how to better time and target messages to the general public and to policy makers during periods of proposed changes to health services.

**Key words:** radiation therapy services; health service management

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### Introduction

In essence, 'bounded rationality involves the decision-maker choosing an alternative intended not to maximise his values but to be satisfactory or good enough...(it) enables the administrator faced with a decision to simplify by not examining all possible alternatives'. [1, p.84] The concept of bounded rationality has been used to describe how information is sourced and prioritised in order to allow policy decisions to be made. Individuals are considered to be 'boundedly rational', in that they wish to achieve a particular policy outcome but may be unsure of how to achieve this or how to process all the information relevant to the issue. [2] Originally pioneered by Simon, [3] bounded rationality rests on several principles, which include that people intend to be rational but cognitive and emotional limitations may make them act in non-rational ways, and that limited attention spans can lead people to choose whichever option is 'good



enough' to meet the minimum aspirational level they have attached to the issue.

The debate over the introduction of radiation therapy services into the North West (NW) Tasmanian region is an example of conflicting priorities: a community desire for more local services versus a stakeholder desire for more centralised services. Prior to 2016 the NW of Tasmania did not have a radiation therapy services and patients from this region were referred to Launceston or Hobart. A media-driven representation of a community desire to have a regional radiation therapy service began to find traction during the 2000s. It was not until the Federal Election campaign of 2010 that funding was finally committed, in the highly marginal electorate of Braddon, which allowed the service to be built. [4]

The community desire for a local radiation therapy service could be seen as reflecting a deep sense of localism. Localism can result from a sense of shared identity and encourages members of the community to become involved in decision-making on issues of local significance. [5] Engagement of the local community in decision-making could achieve, or add to, a balance between government and community needs or expectations.

The community desire for a local service was expressed in several ways, largely via media articles, a petition and a public forum held in 2010. This desire was in contrast to repeated statements by the medical community that a local service was not safe, sustainable or warranted [6-8] and by the State Government that the service needed to be fully funded before it could be considered sustainable. [9, 10] It was also in contrast to the perceived need for such a service by the medical community, given the small population size. [6] However, as discussed by Cairney, [11] efforts by any scientific community to challenge a proposed change based on technical or scientific evidence will fail unless two realities are achieved: that policymakers will never think like scientists; and that there is no point in the policy-making process where scientific evidence can be introduced to manifestly impact the result.

Stakeholders, patients and family members were interviewed to determine if examples of bounded rationality and a sense of localism were evident and contrasted these to the viewpoints stated in documents from the period of the policy debate. By aligning major actors with a particular side of the policy debate, this research examined the reasons behind the use of bounded rationality, the interplay between bounded rationality and localism, and how the

medical community and State Government might have used an understanding of bounded rationality to better target their message to the general public.

### Methods

To identify and understand instances of bounded rationality and localism, evidence was sourced from both semi-structured interviews and document analysis. Documents were sourced from databases, search engines and manual searches and were limited to the year 2000 onwards in order to provide a full decade of debate and consistency to develop prior to the funding commitment made in 2010. Documents included journal articles, government and non-government documents, Hansard, media articles, and media releases and statements made by political candidates, representative bodies and other stakeholders.

Interviews were conducted in 2016 with stakeholders, as well as patients and family members from NW Tasmania. A total of 38 participants were interviewed, comprising 15 stakeholders in 14 interviews, with one interview involving an additional last minute participant, and 16 patients and seven family members across 18 interviews, where some spouses were interviewed together and one family member was interviewed without the patient present. Ethics approval was received from the Human Research Ethics Committee (Tasmania).

Stakeholders were initially identified from the document analysis and invited by letter to participate in an interview. Purposive snowball sampling was then used to identify further possible participants. Stakeholders included health bureaucrats, medical professionals, elected representatives, non-government organisation representatives and committee members. Questions related to the identification of actors and policies that impacted on the design and delivery of cancer services.

An opt-in system was used for recruitment of cancer patients and family, with advertising displayed in the local newspapers, health centres and community centres. Interested parties could then contact to express interest in participating. Participants were restricted to those over the age of 18 who were or had been a diagnosed cancer patient or were the direct family member or carer of a patient. Questions asked during interviews related to the accessibility of the system and suggestions for improving accessibility.

Interview transcripts and documents were read and stakeholders were grouped by profession, with patients forming a separate group. These groups were then analysed

to determine the major beliefs held by each, which were then examined for any perceived instance of boundedly rational behaviour or an expressed sense of localism.

This process involved establishing the scientific evidence presented on the case for radiation therapy services in NW Tasmania and comparing this with the beliefs and actions of policymakers and the local community and the stated rationale for these.

## Results

The document analysis and interviews provide preliminary evidence of one coalition only, constituting state health policy actors – including health bureaucrats or representatives of the State Government – and the health profession. This coalition was bound together by three distinct beliefs:

### 1. Safety and Sustainability: patient safety is compromised if a service cannot be sustained financially or properly resourced.

*The cancer instance in Tasmania is increasing because of an ageing population but it hasn't gotten to the level where it would sustain four linear accelerators in the north of the state, it will only sustain just under three. So one of the machines in Launceston will close down and the one in Burnie will open. (Stakeholder 5)*

*The viability and safety of an isolated single machine radiation oncology unit in the north-west will become a possibility when the critical mass of high specialised staff is achieved at the Launceston General Hospital's Holman Clinic with its third linear accelerator, if cancer rates grow as projected, and if referrals of people with cancer for radiation oncology reach the nationally recommended rate of 52.3 per cent. [12, p.45-46]*

### 2. Recruitment and Retention: recruiting and retaining specialist medical staff is an issue for the NW and would impact sustainability.

*It is expected to be more difficult to recruit to the North West Coast and one of the potential risks with a new North West centre is that specialised staff attracted to this area may come from within the existing staff at the LGH. This may produce a situation where both centres are understaffed. [13, p.2]*

*The major difficulty will be the recruitment and retention of the highly specialised staff necessary to implement and maintain the service. Such a service requires radiation oncologists, specialised nurses, radiation therapists, engineers, medical physicists and other technical staff. All of these personnel are in short supply in Australia. [6]*

### 3. Travel, Transport and Accommodation: providing assistance for patients to travel was a solution to lack of access.

*I actually don't think that distance in Tasmania is a critical issue... if people have greater awareness and understanding then the very small distances that we need to travel in Tasmania pale into insignificance. (Stakeholder 3B)*

*But there are still patients who still need to travel... So if they do have to travel it's about policy decisions making it easier for them to stay overnight and their support person. So it's about equity of access not equality of access. (Stakeholder 6)*

These beliefs showed a focus on the machinations of delivering a radiation therapy service and the prioritisation of patient care over geographic accessibility. These beliefs were demonstrated through evidence on the need for a service and the capacity for it to be delivered in terms of human and financial capital, rather than emotive statements.

What the results did not show, however, was any indication of a competing coalition. There were some shared beliefs amongst members of the community around travel being a burden and around the notion of equity. However, there was no group who advocated consistently for a regional service and came together in non-trivial action. There was one person who organised a petition and a forum. There was one journalist who wrote at least 18 articles framing the issue as one of great importance to the NW and involving significant community involvement:

*The cancer centre fight is an example of how the politics and lobbyists with vested interests can stack the argument. Politicians did not expect everyone in the region almost to a man, woman and child to back up time and again and refuse to budge from a collective demand to have the cancer centre built in Burnie. [14, p.10]*

However, their efforts were made in isolation to each other and with no evidence of community involvement. So how can there be a major change in policy, designed to serve the needs of the community, when no community demand is evident? The results suggest that bounded rationality may have guided policy decision-making in order to facilitate community expectations.

This is highlighted by one member of a non-government organisation involved in cancer services, who stated:

*'There have been times when politics have overridden really what is in the best interests of the client...elections have forced particular policies to be enacted.' (Stakeholder 2)*

Another, being a senior specialist, stated:

*'...money has been inappropriately apportioned to different bits of the state which means that they can't actually provide any proper service anywhere...those sorts of policy decisions are absolutely nonsense.'* (Stakeholder 3A)

The results also showed some strong signs of localism amongst the NW community, even if it was not necessarily demonstrated through a formal, active coalition or lobby group.

Stakeholder 1 was heavily involved in lobbying for radiation therapy services and stated that there was a considerable feeling in the NW that they miss out because they don't have a critical mass. The participant stated that forcing NW residents to travel for radiation treatment was unfair and that a local service needed to be built to deliver equity. *'If people needed to come from Melbourne to Burnie for treatment an hour's flight and back is less than having to go through to Launceston or Hobart. So there is a possibility of expanding the clientele.'* To summarise, their argument was that people from the NW should not be made to travel to Launceston (being as little as 50 minutes away) but that people from Victoria could travel to NW Tasmania to receive treatment and that this was acceptable. This points to the irrationality and contradictory nature of some beliefs, consistent with the notion of boundedly rational decision-making.

Interestingly, not all the patients interviewed showed a strong sense of localism. Indeed, some were quite vocal in their opposition. One patient stated:

*'Regional parochialism has, for want of a better word, bugged the hospital system in Tasmania... They've wasted so much money where they could have a damn good helicopter service.'* (Patient 12)

## Discussion

The health and policy coalition could, in terms of bounded rationality, be seen as the 'scientific community' in this particular health sphere. They were the medical professionals and health bureaucrats who understood intimately the service and its complexities. The Tasmania Government (as a state health policy actor) should therefore have been both a coalition member as well as a policy maker, thereby strengthening the link between the 'scientific community' and the decision-making authority. This was true in essence. However the Federal Government's takeover of the issue in the 2010 Federal Election, by committing Federal funding for a state responsibility, changed the dynamics so that the true policymaking power lay with the most hierarchically superior level of government.

The absence of a second coalition to lobby for policy change leads to the question of whether change was agitated for by something or someone other than a consumer coalition. There is a possible role of the media in framing and promoting the issue of radiation therapy services, giving the impression of widespread community support when little more than general community interest existed. Or it could even be that the media, in a demonstration of bounded rationality, stated that there was a community desire for this radiation therapy service. However, in reality there is little evidence of having been a 'community desire' at all when it came to this issue.

In terms of understanding the actions of policymakers, bounded rationality can be seen. Acting on the desire to be elected or re-elected, the political parties vying for power in the 2010 Federal Election gathered enough information to form the basis of a decision, one that could win public support. This decision was that the community desired a radiation therapy service in the NW and that building a service in that region was the pre-packaged solution. Other alternatives, regardless of how clearly they were articulated or how strongly these were promoted by the 'experts' in the field, could not find traction in the midst of this boundedly rational decision-making.

But would this change have occurred without the intervention of the Federal Government? The evidence here is mixed. On one hand, Braddon was a marginal seat in what was going to be a close election. On the other hand, funding had previously been concentrated on the Launceston service, including a 2007 commitment that led to a third linear accelerator there. Significantly, discussion over the possible funding of radiation therapy services only became noticeable after a petition was presented to State Parliament in 2010 on the eve of a public forum in the lead up to the election. This indicates that the move from no radiation therapy to a radiation therapy service reached a marked increase in momentum during the Federal election campaign of 2010, after no clear timeline from the State Government for achieving this change. Indeed, part of the decision to place a third linear accelerator in Launceston, rather than establishing a service in the NW, had come down to issues of sustainability and recruitment, indicating the State Government concurred with the views of the health community. [13] Therefore, change was clearly instigated at a Federal level.

Understanding the reality of bounded rationality in policymaking allows health professionals and those involved in health policy to be more strategic in what they say and

when they say it. As Cairney [11] states, there is no one point in the policy process at which scientists or experts can step in and have a significant effect on the outcome. The process is more chaotic, more emotive and less logical than that. By understanding the limitations to a policymaker's receptiveness to new information, even in the face of credible new information, health experts can target messages more effectively.

Skinner [15] discusses the idea of being more strategic using the concept of 'defensive localism' to discuss proposed changes to local health networks in Canada. Some of the networks affected, rather than fighting the changes, used the opportunity to secure additional funding in return for their acquiescence. Therefore, if health professionals or managers could frame the issue in terms of what the affected groups might be able to secure or gain if they supported evidence-based changes then these groups might take that opportunity. Likewise, health professionals and management might realise that their organisations are the ones needing to acquiesce and could use this understanding to bargain for a better outcome. The consequence of using this understanding and being more strategic with policy actions may well mean a more safe and sustainable service for patients, even if that patient group is seemingly lobbying for a different outcome.

### Conclusion

This paper has examined how political strategy used to win support in a marginal seat during a marginal election reveals the use of boundedly rational decision-making in the establishment of radiation therapy services. The efforts of the scientific community, namely health bureaucrats and health professionals, were to highlight the lack of sustainability and safety in such a service and the ongoing issues of recruiting and retaining specialist oncology and radiation therapy staff. The Tasmanian Government had also refrained from moving forward on establishing a radiation therapy service in the NW for the same reasons. It was not until the commitments made by the Federal Government in 2010 that the Tasmanian Government was left with no choice but to proceed.

Yet, the decision to commit funding does not appear to be based on any evidence presented that there was a need for this service in the NW region. The evidence, indeed, supported the contrary. What was evident was a sense of localism in the region that made the establishment of radiation therapy services a pre-packaged solution aimed at meeting the aspirational objectives of the Federal

Government to be re-elected in 2010. This article provides health service professionals and managers with an opportunity to understand the political, boundedly rational motivations that underpin policy change and the incorporate this understanding into their own policy objectives.

### Competing Interests

The authors declare that they have no competing interests.

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